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Exploring the Experiences of Providing Care at Home in Rural Areas for a Partner with Moderate to Severe Dementia: An Interpretative Phenomenological Analysis

and Clinical Research Portfolio

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July 2017

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Chapter 1: Systematic Review

# The Efficacy of Educational Interventions in Changing Staff Attitudes Towards Older People's Sexuality in Residential Care Settings: A Systematic Review

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## ABSTRACT

### Introduction

Sexuality within older adult residential care facilities is rarely discussed. There is a growing body of literature that has sought to understand what the attitudes of care staff are towards residents' sexuality and sexual expression. Overall attitudes tend to be positive but there is a frequent and consistent mention of the need for staff to have further education and training. This systematic review will review the efficacy of educational interventions in changing staff attitudes towards sexuality in older people.

### Methods

A systematic search of databases CINAHL, EMBASE, PsychINFO and Web of Science was conducted. Studies were reviewed against the inclusion and exclusion criteria and ten studies were included for final review.

### Results

Six of the included studies report a statistically significant difference in scores towards more permissive attitudes regarding sexuality following educational workshop interventions. Five of the included studies also report a change in knowledge relating to older people's sexuality following intervention.

### Conclusions

This review demonstrates that educational interventions can successfully change staff attitudes towards older people's sexuality in residential care settings. Limitations of the review and suggestions for future research are discussed.

## INTRODUCTION

Sexuality, defined as “a central aspect of humanity throughout life, encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure and reproduction” (Glasier et al., 2006, pp. 1596) has historically been ignored and under researched in older individuals (Elias and Ryan, 2010). Intimacy and sexuality in older people are rarely discussed topics and stereotypical attitudes often take precedence (Langer, 2009). However, more recently, there is growing recognition within the literature that sexuality remains important throughout the ageing process with sexual thoughts and desires persisting into advanced age (Hodson and Skene 1994; Wiley and Bortz 1996).

The now well-documented demographic shift of the increasing older adult population will result in escalating care needs and service requirements of this population in future years (Anderson and Hussey, 2000). Consequently, there will be a rise in the number of individuals residing in care settings in the later stages of their lives. There has been a cultural shift and generational change with regards to sexuality and sexual expression over recent eras. The current younger adult population have experienced and lived with more liberal attitudes towards sexuality and sexual expression in contrast to the existing older generation (Bauer et al., 2013). Subsequently, care facilities will be required to understand and support residents to express their sexuality within care, in order to address this important aspect of residents’ quality of life.

The definition of sexuality within the nursing home ought to have a wide focus incorporating intimacy, affection and companionship as well as sexual expression (Hajjar and Kamel, 2003; Nay, 1992). Despite recognized benefits of sexual expression to quality of life, nursing home residents remain one of the most sexually deprived groups of people within society. Barriers to sexual expression in the nursing home include staff attitudes,

attitudes of family members, lack of privacy and the lack of a willing and able partner (Hajjar and Kamel, 2003).

Staff in care settings are responsible for not only meeting the basic care needs of residents but in promoting and supporting human rights, dignity and privacy through a person centred approach. Staff attitudes are key in determining acceptance, intervention and understanding of sexuality. Their attitudes towards sexuality will determine whether a sexual act within a care home is viewed as healthy sexual expression or is deemed 'inappropriate sexual behaviour'. Staff attitudes towards sexuality will subsequently also have an impact as to whether and how they intervene and approach the act. There is suggestion within the literature that staff typically view sexual expression in care homes as problem behaviour as opposed to a desire for love and intimacy (Hajjar and Kamel, 2003).

Many of the staff in care home settings report difficulties, confusion, embarrassment and helplessness when managing sexual expression in residential settings (Ehrenfeld et al., 1997). Due to the reluctance to acknowledge and address the issues of sexuality within care homes, there is a lack of consistent policy, procedure and guidelines that address the issue. Legislation, National Care Standards and government guidance do not generally discuss the topic (Royal College of Nursing, 2011).

Residents with dementia and other cognitive disorders related to old age add a further complexity to the issue as they may experience a lack of capacity to consent to sexual acts (Bartlett, 2010). They may also be more likely to present with disinhibited behaviour that is of a sexual nature. Concerns about litigation and organizational standards to protect residents from harm may reflect some of the cautionary attitudes and actions towards sexuality in residents with dementia. However, an overly cautious attitude to sexual expression could be an oversimplification of the issue denying older people both with and

without dementia the right to intimacy and sexual expression. There is significant complexity associated with staff balancing residents' rights to sexual expression and safeguarding all residents from harm (Roelofs et al., 2015).

An increase in knowledge about sexuality has been linked overall to more permissive and open attitudes towards sexual expression in older people (Di Napoli et al., 2013). Much of the research that has sought to understand what the attitudes of care staff are towards sexuality in residential care facilities has identified a need for further training and education on the issue (Mahieu et al., 2016; Bouman et al., 2007; Ehrenfield et al., 1999; Walker et al., 1998).

### **Rational for the current review**

Two recent reviews of the subject area have been conducted. Haesler et al. (2016) reviewed the knowledge and attitudes of healthcare professionals towards the sexuality of older people. They concluded that there is a lack of knowledge and confidence in the area and recommended better role modelling and education in order to improve knowledge and attitudes. The remit of their review was wide in order to determine the overall attitudes, however, they did report on one study (Bauer et al., 2013), which used an intervention to improve attitudes.

Mahieu et al. (2011) provide a review of the knowledge, attitudes and experiences of nursing staff towards sexuality in institutionalized older people. The authors concluded that more in depth qualitative studies are required and that a more accurate educational programme could increase knowledge of sexuality in older people and encourage more positive and permissive attitudes. The focus of the review was to determine overall attitudes and experiences. However, the review does comment on four intervention studies

which indicated that educational programmes could effectively shift sexual attitudes towards older people in the direction of increased permissiveness.

It has been established that there is a need for increased knowledge and education amongst care staff in relation to the sexuality of older people. In order to develop training programmes and educational interventions to increase the knowledge of care staff of this issue, it is important to systematically review the existing literature to determine if educational interventions to date have been successful in changing attitudes and to ascertain what characteristics of the intervention have led to effective change. As far as the researcher is aware there have been no systematic reviews conducted to date which have specifically reviewed the efficacy and characteristics of interventions to change attitudes of care staff towards older people's sexuality.

### **Review Aims**

This systematic review aims to identify studies that have sought to change the attitudes of care staff to residents' sexuality through increasing their knowledge and education about the issue. Overall the aims of the review are to:

- Systematically identify and synthesize studies which have used interventions to change staff attitudes towards sexuality
- Assess the efficacy of interventions to change attitudes towards residents' sexuality
- Identify which characteristics of the interventions have led to effective change
- Appraise the quality of the studies, highlighting methodological strengths and weaknesses

## METHODS

### Search strategy

Electronic databases MEDLINE, CINAHL, PsychInfo and Web of Knowledge were systematically searched in order to identify relevant studies. The following search terms were used: [attitude\* OR belief\* OR opinion\* OR knowledge\* OR perspective\*] AND ["nurs\* home" OR "care home" OR "residential home" OR "home for the aged" OR "long term care"] AND [sexual\*]. Full search strategies for each database are included in the Appendix 2. The records generated through the searches were exported to RefWorks and duplicates were removed. Articles were initially screened for relevance by title and abstract before the remaining full- text articles were evaluated against the inclusion and exclusion criteria. In cases where it was not clear, the paper was discussed with a member of the research team. In order to ensure that all available literature had been identified, Ethos database for unpublished theses was reviewed. Two journals 'Educational Gerontology' and 'Gerontology and Geriatrics Education' were hand searched for additional studies. Finally, the reference sections of the final articles were hand searched in order to obtain any additional articles. Once this process was complete 10 articles were included in the final synthesis. The identification and screening process is outlined in Figure 1. which followed PRISMA guidelines (Moher et al., 2009).

### Inclusion Criteria

- Studies in English
- Articles in peer reviewed journals
- Articles which used a group educational intervention where the aim was to change staff attitudes towards sexuality
- Articles which focus on interventions in residential care
- Unpublished theses

### Exclusion Criteria

- Previous reviews, book chapters and case studies

- Articles which focus solely on education interventions for the older person or family members
- Articles which focus on interventions in non-residential settings

### **Procedure**

The final ten articles included in the synthesis were reviewed and quality rated using an adapted version of the Downs and Black (Downs and Black, 1998) checklist for non-randomised studies (provided in Appendix 4). Adaptions were made in order to address the aims of the current review. In order to ensure the validity and reliability of the rating scale and to control for bias, 50% of the studies were co-rated by a second researcher. Inter-rater reliability was calculated to be  $K = 0.749$ ,  $p < .0005$ . Discrepancies about ratings were discussed and agreement was reached. Item quality ratings for each study are provided in Appendix 5.

### **RESULTS**

Table 1 provides an overview and details the included 10 studies.

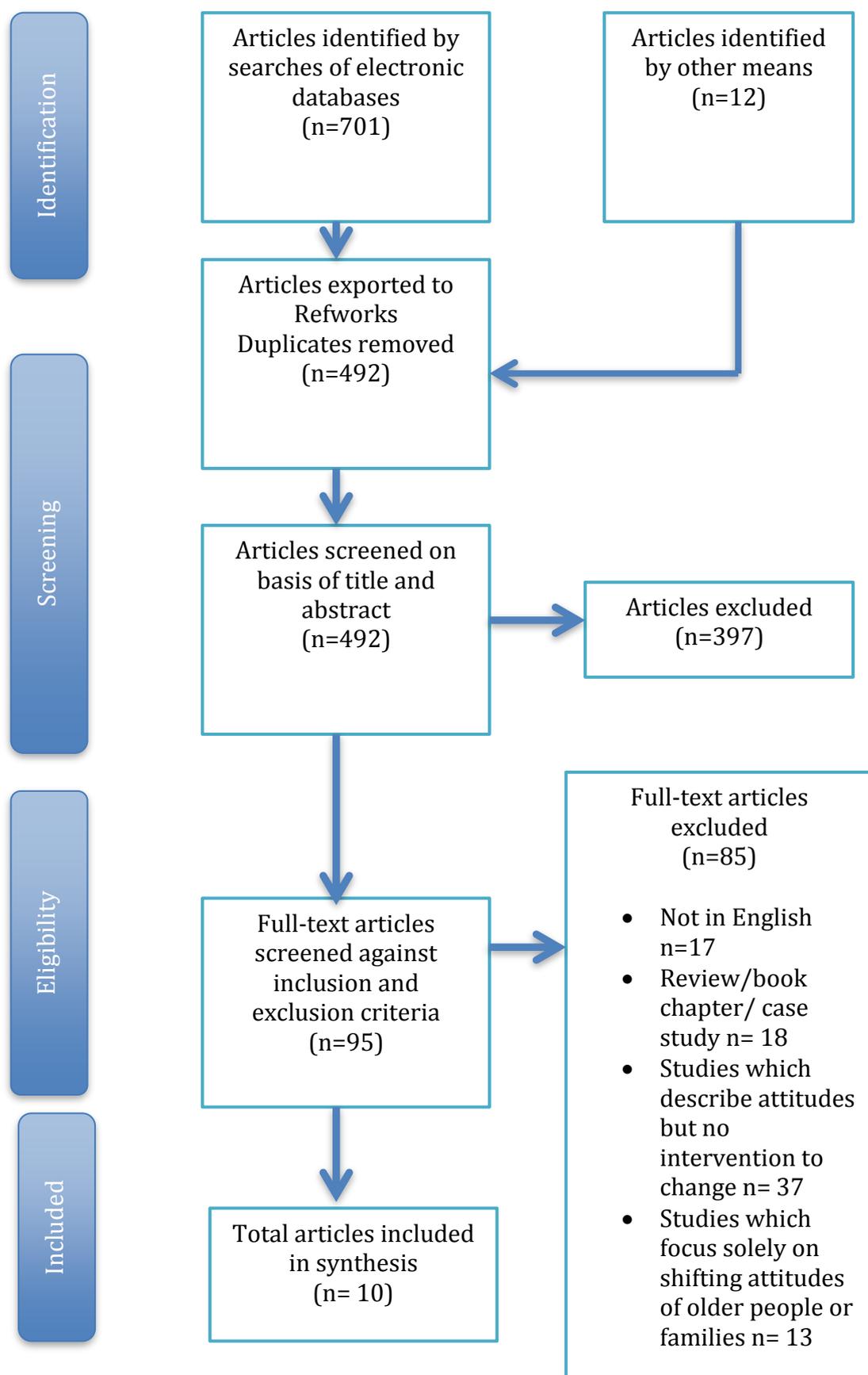


Figure 1: PRISMA Flow diagram of paper identification

Table1: Overview of studies

Author, year (country) Quality rating	Study design	Participant characteristics	Intervention description	Attitudinal Measure	Major findings	Strengths & Weaknesses
Aja and Self, 1986  (USA)  Good  78%	Randomized control study.  Two experimental groups (implicit and explicit) and one control group. The control group completed the outcome measures but did not attend the workshop intervention.	n=32  Age range 18-62 (mean= 39 years)  Job roles: nurses' aides, dietician aides, registered nurses, social workers and nursing home administrators.  Participants all from one nursing home.  Years of experience: most participants had not completed more than one year of training for licensed nursing.	<u>Implicit group</u> 14-hour workshop split over 2 days. Exposure to sexually implicit materials usually films and participants encouraged to react to those materials in small groups.  <u>Explicit group</u> 14-hour workshop split over 2 days. Exposure to sexually explicit materials usually films and participants encouraged to react to those in small groups  Both groups also completed exercises on values, sexual language and touching.	SKAT  LTK	Newman-Keuls post hoc comparisons indicated that both the implicit and explicit treatment groups performed significantly better than the control group ( $p < .05$ ) on the Knowledge Scale of the SKAT.  Analysis of the LTK Attitude Rating Scale indicated no significant differences between implicit, explicit and control group perceptions	<u>Strengths</u> <ul style="list-style-type: none"> <li>Control group</li> <li>Variety of intervention methods evaluated</li> </ul> <u>Weaknesses</u> <ul style="list-style-type: none"> <li>Reporting of results</li> <li>The use of the LTK which was developed by the authors for the study</li> </ul>
Bauer, McAuliffe, Nay and Chenco, 2013  (Australia)	Quasi-experimental	n= 112  Age range= 18- 51+  Female= 102 Male= 8 Job roles: registered	Three hour workshop covering topics including attitudes towards sexuality in older people, sexual expression in residential care, resident's rights and staff responsibilities. 50 minute	ASKAS  8/20 items from SAID	Significant difference in comparison of scores on the total ASKAS score from pre- to post- intervention ( $z = -2.541, p = .011, r = .17$ )  Significant difference on 5	<u>Strengths</u> <ul style="list-style-type: none"> <li>Large sample size</li> <li>Addresses limitations of the study</li> </ul> <u>Weaknesses</u>

Good 83%		nurses and enrolled nurses  Years of experience: 75% of participants six or more years'	DVD presentation by a lawyer with expertise in aged care.		out of 8 items on the SAID	<ul style="list-style-type: none"> <li>Limited reporting of SAID statistical analysis</li> </ul>
Livni, 1984 (South Africa)  Adequate  67%	Quasi-experimental  Non- randomized control group. The control group completed the questionnaire but did not undertake the educational program	n=210  Job roles = nursing staff  Nursing staff from eight long-term care homes	Educational program of video clips and discussions facilitated by a presenter who ensured specific topics were addressed.	DEMASKAS	<p>Significant differences were found on the knowledge subscales from pre- to post- test <math>F [1,181] = 39.15, p &lt; .0001</math> and pre- to post-test x treatment group <math>F [1,181] = 19.08, p &lt; .0001</math></p> <p>Significant differences were found on the attitudinal subscales from pre- to post-test; <math>F = 33.42, p &lt; .001</math> and a significant pre- post-test interaction effect with treatment group <math>F = 72.38, p &lt; .001</math></p>	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>Control group</li> <li>Participants recruited from a number of different care homes</li> </ul> <p><u>Weaknesses</u></p> <ul style="list-style-type: none"> <li>Limited reporting of participant demographic details</li> </ul>
Steinke, 1997 (USA)  Adequate	Pilot study	n=10  Female= 8 Male= 2  Age range 29-62 (Mean= 39.2 years)	Two one-half day (one week apart) education sessions on sexuality and aging. Educational methods included lecture, discussion, audio-visual aids, a game and printed materials	ASKAS	<p>Knowledge about sexuality significantly increased pre- to post- test; <math>t (9) = 4.27, p = .002</math></p> <p>No significant change occurred in attitude scores</p>	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>Variety of educational methods used in intervention</li> </ul> <p><u>Weaknesses</u></p>

69%		<p>Job roles: registered nurses, licensed practical nurses, certified medication assistants, certified nursing assistants</p> <p>Years of experience: Range 1-20+years</p>			<p>from pre- to post-test; <math>t(9) = .72, p = .49</math></p>	<ul style="list-style-type: none"> <li>• Pilot study therefore small sample size</li> <li>• No change to attitudes was observed post intervention</li> </ul>
<p>Mayers and McBride, 1998</p> <p>(USA)</p> <p>Poor</p> <p>31%</p>	Pilot study	<p>n= 27</p> <p>Job roles= psychiatrists, non-psychiatrist physicians, registered nurses, nurse administrators, psychologists, social workers, therapists and students</p>	<p>Three hour workshop involving group activities, open discussions and handouts to consolidate learning.</p>	<p>A standard hospital feedback form</p> <p>A brief sexual attitudes survey</p>	<p>Qualitative statements only:</p> <p>35% of participants described the workshop as changing their awareness of their own attitudes toward geriatric sexuality.</p> <p>“Respondents reported that the workshop helped them feel more comfortable with sexual issues”</p>	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>• 5 month follow up (20/27 participants completed)</li> <li>• Range of professionals participated</li> </ul> <p><u>Weaknesses</u></p> <ul style="list-style-type: none"> <li>• Limited reporting of results</li> <li>• No statistical analysis</li> <li>• Attitudinal measure not validated</li> </ul>
<p>Jones and Moyle, 2016</p> <p>(USA)</p>	Sequential mixed-methods design	<p>n=42</p> <p>Age range 16-67 (mean =38 years)</p>	<p>e-Learning resource to support self-directed learning. The resource is built around four learning modules:</p>	<p>ASKAS</p> <p>SAID</p>	<p>Significant differences were found between participants’ pre- and post-ASKAS (<math>Z = -2.57, p = .01</math>)</p>	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>• Mixed methods design</li> <li>• Use of validated</li> </ul>

<p>Good 75%</p>		<p>Females n= 38 Males n=4</p> <p>Job roles: 16 nursing students and 26 registered nurses, enrolled nurses, personal care workers and diversional therapists</p> <p>Years of experience: Range 0 -25 years (average 5.4 years)</p>	<p>1) Intimacy, sexuality and sexual behaviour 2) Dementia and the expression of sexuality 3) Ethical considerations: policy guidelines development for sexualities and dementia in care settings 4) Developing sexualities and dementia policy guidelines for care practice</p> <p>Case studies, activities and resources were provided to consolidate learning.</p>		<p>and SAID (<math>Z = -3.14, p = .002</math>) attitude scores.</p> <p>Significant differences were found between participants' pre- and post-ASKAS (<math>Z = -2.82, p = .005</math>) knowledge scores.</p> <p>Three key themes determined from qualitative analysis: Being happy and well; Conferring with family and Workplace policy</p>	<p>attitudinal measures</p> <p><u>Weaknesses</u></p> <ul style="list-style-type: none"> <li>• No follow up to determine if the shift in attitudes remained over time.</li> <li>• Limited in discussions that could be had between fellow participants or facilitators due to methodology.</li> </ul>
<p>White and Catania, 1982 (USA) Good 75%</p>	<p>Randomized control trial</p> <p>Assigned by randomized blocks procedure blocking on education</p>	<p>n= 30</p> <p>Mean age experimental group= 32.7 years Mean age control group= 33.1 years</p> <p>Job roles: Administrators, registered and practical nurses and activity directors</p>	<p>Three sessions that included lectures on aspects of sexuality in aging, video clips of expert discussions, films, a simulation exercise on problem situations encountered by older people and informal discussions and questions with a facilitator.</p>	<p>ASKAS</p>	<p>Significant effect between experimental and control group on knowledge scores (<math>F = 35.97, p &lt; .0001</math>) The correlation between pre- and post-test knowledge score within condition was <math>r = .79</math> for the control group and <math>r = .11</math> for the experimental group</p> <p>Significant effect between experimental and control group on attitudinal scores (<math>F = 5.87, p &lt; .02</math>) The correlation between pre-</p>	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>• Control group</li> <li>• Use of a validated outcome measure</li> </ul> <p><u>Weaknesses</u></p> <ul style="list-style-type: none"> <li>• No post intervention follow up to determine if change is sustained after a period of time.</li> </ul>

					and post-test attitudinal score within condition was $r = .44$ for the control group and $r = .07$ for the experimental group.	
Walker and Harrington, 2010 (USA) Adequate 64%	Pilot study	n = 109  Females n = 99 Males n = 10  Age range = 20-69 (Mean = 38.47 years)  Job roles: registered nurses, licensed practical nurses, nursing assistants, activity aides and other professionals.  Years of experience ranged from 1 to 33 (Mean = 9.14 years)	Four modules that included videotapes of interviews with staff and residents at several different care homes, case handouts and discussions led by the facilitator.	KATES	Overall scores improved from pre- to post-test ( $SS = 288.12, p < .0005$ ). On individual modules, score improved in three modules but remained stable for one module	<u>Strengths</u> <ul style="list-style-type: none"> <li>• Large overall sample size</li> </ul> <u>Weaknesses</u> <ul style="list-style-type: none"> <li>• Pilot study</li> <li>• Different participants completed different modules. Some completed more than one</li> </ul>
Reingold and Burros, 2004 (USA) Poor 11%		Job roles = nurses, aides, physicians, social workers, dieticians and activity co-ordinators.  Focus on one nursing home	The policy of the home was discussed before a facilitated discussion around a range of vignettes.	None	Qualitative statements only: "The staff education was received very positively by staff, who were relieved to have clearer guidelines on how to respond to situations which had made them anxious"	<u>Strengths</u> <ul style="list-style-type: none"> <li>• Use of vignettes in educational intervention</li> </ul> <u>Weaknesses</u> <ul style="list-style-type: none"> <li>• No statistical analysis</li> <li>• No outcome</li> </ul>

						measure <ul style="list-style-type: none"> <li>• No specific demographic details reported</li> </ul>
West, 1983 (USA)  Poor  19%		Job roles= administrators, nurses, activity directors and social workers.	Simulation methodology was used. Participants were provided with a 'life situation' followed by an assignment to find a solution to the problem. Further information was required to be obtained from other 'people' involved in the situation. Participants were required to formulate a plan before discussing with the larger group.	None	Qualitative statements only:  "Learning objectives were met through the acceptance of sexual behaviour in the ages, becoming aware of the needs older people have for romance, privacy and sexual expression and understanding age related changes in sexuality".  "The goal of an interdisciplinary approach to working with older people was also met".	<u>Strengths</u> <ul style="list-style-type: none"> <li>• Novel methodology</li> <li>• Included the importance of a multi-disciplinary approach</li> </ul> <u>Weaknesses</u> <ul style="list-style-type: none"> <li>• No validated outcome measure used</li> <li>• No statistical analysis</li> <li>• Limited demographic details about participants reported</li> </ul>

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Key: ASKAS= Aging Sexual Knowledge and Attitudes Scale; DEMASKAS= Aging Sexuality Knowledge and Attitude Scale for Dementia; SAID= The Staff Attitudes about Intimacy and Dementia Survey; KATES= Knowledge and Attitudes Toward Elderly Sexuality; LTK= The LTK Attitude Rating Scale; SKAT= The Sex Knowledge and Attitude Test

## **Participants**

A total of 572 staff members participated in the studies included in this review. The age range was 16-69 years. The majority of participants were in a nursing job role at the time of participation including registered nurses, licensed practical nurses, nursing assistants and student nurses. Four of the studies reported that they also included administrators (West, 1983; Aja and Self, 1986; Mayers and McBride, 1998; White and Catania, 1982). The number of years of experience of providing care to older people was reported in five studies (Aja and Self, 1986; Bauer et al., 2013; Steinke, 1997; Jones and Moyle, 2016; Walker and Harrington, 2010). The number of years of experience ranged from 0 to 33 years across the studies.

## **Measures**

Four studies (Bauer et al., 2013; Steinke, 1997; Jones and Moyle, 2016; White & Catania, 1982) used the Aging Sexual Knowledge and Attitudes Scale (ASKAS) (White and Catania, 1982) to measure attitudes towards sexuality. It is reported to have good reliability and validity, however, a criticism noted of this scale is that only one of the items on the scale refers to dementia. Two studies (Bauer et al., 2013; Jones and Moyle, 2016) addressed this issue by also incorporating items from The Staff Attitudes about Intimacy and Dementia Survey (SAID) (Kuhn, 2002) and Livni (1994) adapted a version of the ASKAS to include dementia related items, Aging Sexuality Knowledge and Attitude Scale for Dementia (DEMASKAS). Walker and Harrington (2010) assessed attitudes using the Knowledge and Attitudes Toward Elderly Sexuality (KATES) (Walker et al., 1998). Aja and Self (1986) used both The Sex Knowledge and Attitude Test (SKAT) (Miller and Lief, 1979) and The LTK Attitude Rating Scale which was developed by the authors. A non-validated brief attitudes towards sexuality survey was used in one study (Mayers and

McBride, 1998). Finally, Reingold and Burros (2004) and West (1983) did not use a standardised attitudinal outcome measure to assess change in attitudes.

### **Interventions**

All of the interventions described in the included studies were of a workshop format. Typically a range of methodologies were used in each workshop such as presentations, vignettes, facilitated discussions, watching of video clips and the use of written hand-outs to help to facilitate a better understanding of older people's sexuality. Jones and Moyle (2016) used an online e-learning resource to disseminate workshop material whilst all other workshops were delivered in person.

### **Data synthesis**

The identified studies in this systematic review are notably varied with regards to their methodology, study design, quality and statistical analysis. As a result, a narrative synthesis approach was used to collate information about the studies. Narrative synthesis uses a textual approach to synthesis the findings of the included studies (Rodgers et al., 2009). For clarity, each of the aims of the systematic review will be discussed in turn.

### **Appraise the quality of the studies, highlighting methodological strengths and weaknesses**

The quality ratings for each study are summarised in Table 1. Item quality ratings are provided in Appendix 5. The quality of the studies varied; four studies were reported to be of good quality (Aja and Self, 1986; Bauer et al., 2013; White and Catania, 1982; Jones and Moyle, 2016), three studies were of adequate quality (Linvi, 1994; Steinke, 1997; Walker and Harrington, 2002) and three studies were of poor quality (West, 1983; Reingold and Burros, 2004; Mayers and McBride, 1998). Methodological strengths included the use of control groups (Aja and Self, 1986; Linvi, 1994; White and Catania, 1982), clear reporting of aims and hypotheses (Aja and Self, 1986; Bauer et al., 2013;

Linvi, 1994; White and Catania, 1982; Jones and Moyle, 2016), the use of a longitudinal follow up (Mayers and McBride, 1998) and discussions about the limitations of the study (Bauer et al., 2013; Steinke, 1997; Walker and Harrington, 2002; Jones and Moyle, 2016). Methodological weakness included the lack of an outcome measure to determine attitudinal change (West, 1983; Reingold and Burros, 2004; Mayers and McBride, 1998) and a failure to use appropriate statistical analysis (West, 1983; Reingold and Burros, 2004; Mayers and McBride, 1998).

The highest quality rated study (Bauer et al., 2013) provided a thorough scientific background and rationale for the study, used standardised outcome measures to assess attitudinal change, reported a clear description of the intervention and discussed both limitations and strengths of the research. The lowest quality rated study (Reingold and Burros, 2014) failed to use an outcome measure to determine change in attitudes and did not clearly describe the intervention used or the participants that took part.

### **Assess the efficacy of interventions to change attitudes to residents' sexuality**

Six of the included studies (Aja and Self, 1986; Bauer et al., 2013; Linvi, 1984; Jones and Moyle, 2016; White and Catania, 1982; Walker and Harrington, 2002) report a statistically significant difference in scores towards more permissive attitudes regarding sexuality following intervention. Attitudes were determined by the use of the ASKAS in three of the studies (Bauer et al., 2013; Jones and Moyle, 2016; White and Catania, 1982). Aja and Self (1986) measured attitude change by the use of the SKAT and the LTK, Linvi (1984) used the DEMASKAS and Walker and Harrington (2002) used the KATES. These six studies, which found a statistically significant shift in attitudes, are six of the seven most highly rated studies included in the review in terms of quality. The fifth most highly rated (Steinke, 1997) did not find a significant difference in attitudes measured by the ASKAS towards sexuality following intervention. The author concluded that the attitudes of

participants were sufficiently tolerant before intervention, which accounted for no significant change in attitudes being determined post intervention. Mayers and McBride (1998) report that 35% of participants described the intervention as changing their attitudes towards older adult sexuality, however, the study does not provide any statistical analysis to support this. Two studies (Reingold and Burros, 2004; West, 1983) did not provide quantitative results and instead report qualitative statements to indicate outcomes post intervention such as “ [participants] became aware of the needs older people have for romance, privacy, sexual expression and understanding age related changes in sexuality” (West, 1983, pp. 64). These three studies (Mayers and McBride, 1998; Reingold and Burros, 2004; West, 1983) are the lowest rated quality studies included in the review. Although these studies lack scientific rigour to statistically determine the efficacy of interventions, they provide qualitative information about attitude change and useful information can still be extracted from their methodology, for example Mayers and McBride (1998) are the only study to include a 5-month follow up post intervention.

In addition to the shift in attitudes, five of the included studies (Aja and Self, 1986; Linvi, 1984; Steinke, 1997; Jones and Moyle, 2016; White and Catania, 1982) also report on a change in knowledge following intervention. White and Catania (1982), Steinke (1997) and Jones and Moyle (2016) used the ASKAS to measure change in knowledge, Aja and Self (1986) measured it using the SKAT and Linvi (1984) used the DEMASKAS. All of these studies report a statistically significant increase in knowledge related to aspects of older adult sexuality post intervention.

### **Identify which characteristics of the interventions have led to effective change**

A further aim of the review was to determine which aspects of the interventions provided had led to a change in attitudes. All of the included studies used a range of methodologies within their workshop interventions. The intervention used in the highest quality rated

study (Bauer et al., 2013) was a three-hour workshop that included a range of topics such as sexuality and normal ageing, sexual expression in residential care and sexual stereotypes. The intervention also included a fifty-minute DVD presented by a lawyer which covered legal issues such as capacity and consent. Steinke (1997), rated as adequate quality, described their intervention as two half-day sessions, which included lectures, discussions, a game and the use of audio-visual aids. Interestingly, this study did not find a significant change post intervention. Typically the included studies did not report on which aspects or indeed all of the aspects of the workshop that led to attitudinal change. One of the studies (Bauer et al., 2013) reported on more specific aspects of change. They determined that attitudes improved the most for ASKAS (White, 1982) items “staff understanding of sexual needs” and for the dementia specific items and the item on homosexuality on the SAID (Khun, 2002). The authors also commented that staff attitudes towards their own relatives may be more impervious to change compared to attitudes towards residents whom the staff care for, with the emotive element identified as the key component. Overall, the conclusions which can be drawn for this particular aim are limited due to only one of the studies reporting on specific details about the change process. Only Bauer et al. (2013) provide initial suggestions about which characteristics have led to attitudinal change.

## DISCUSSION

This review has determined that educational interventions have the potential to change residential care staff's attitudes towards older people's sexuality in a more permissive direction. This supports previous research in the area that determined that an increase in knowledge about sexuality has been linked overall to more permissive and open attitudes towards sexual expression in older people (Di Napoli et al., 2013).

The review has shown that workshop interventions are an effective methodology for instigating change in knowledge and attitudes. The workshops discussed a range of topics including ethical considerations, psychoeducation about sexuality in older people and roles and responsibilities of staff, and were effective at shifting staff attitudes in a more permissive direction. The use of workshops has been described in other clinical areas as being an effective training method to improve attendees' knowledge, attitudes and confidence (Walter et al., 2005). The review also identified a gap in the literature with regards to the longevity of a change of attitudes and it is suggested that this is where future research should focus on. Research in other clinical areas has shown that extended contact, through follow-up consultation, supervision or feedback is necessary for the long-term adoption of knowledge and skills (Bennett-Levy and Padesky, 2013).

A number of the studies in this review (Bauer et al., 2013; Jones and Moyle, 2016) acknowledge the limitation of their own work in determining whether the intervention has led to any behavioural changes to the way in which staff approach sexuality in residential settings. The challenges of conducting research in residential care homes have been highlighted in a previous review of the literature (McCabe et al., 2007). Some of the considerations the authors reported included difficulties with repeated measures designs given the continued cognitive decline of residents, the variation between residential homes such as size, staff numbers and client group which can mean training programmes are

tailored to the needs of the home but to the detriment of standardization for research purposes. Additionally the reliance on staff members who have attended training to record behaviours on checklists introduces bias as they may selectively record fewer behaviours occurring. Overall, this may make it difficult to address one of the recommendations of this review, which is to determine whether attitudinal changes lead to practice changes within residential homes. Although it may prove challenging, it will be important to consider methods of increasing the research that is conducted with this population and setting given the predicted increase in the population that will be living in care in the coming years and the lack of research to date conducted in care homes.

### **Strengths and limitations of this review**

This review has systematically searched and appraised the available literature in the subject area. The literature search has been thorough and has included a search of unpublished theses and a hand search of two of the most relevant journals. The small numbers of studies in the subject area limit the generalizability of the conclusions that can be drawn. The quality of the studies is varied across the identified studies. Three of the included studies have been rated poor on a quality rating scale and therefore the review has been tentative about drawing conclusions from these studies. Specifically, studies that have not used an attitudinal outcome measure to determine the change in attitudes should be interpreted with caution (West, 1983; Reingold and Burros, 2004; Mayers and McBride, 1998). Only two out of the included ten studies were randomised control trials, which further limits the results of the review. Future randomised controls in this study area would assist in minimising selection bias, increasing the effect sizes of results found and improving the overall quality of studies.

### **Clinical implications**

A typical component of clinical psychologists' work in older adult services is to provide interventions for behaviours which older people are presenting with in residential care

settings which staff are finding difficult to manage. Specifically staff may be asked to provide interventions in relation to 'inappropriate sexual behaviour' that is being displayed. Older residents who display forms of sexual expression can often be regarded as having a behavioural problem and may even be tranquilized in an attempt to prevent sexual expression (Deacon et al., 1995). This review has highlighted that educational interventions have the potential to shift staff attitudes towards a more permissive stance. As the attitudes of staff will influence the actions that they will undertake with regards to an episode of sexual expression from an older person clinical psychologists may consider assessing the attitudes of care staff towards sexuality at the point of referral and provide appropriate intervention as necessary. This may help to limit the pharmacological interventions that are used in order to control this behaviour and help to increase staffs' overall psychological knowledge about older people's sexuality.

### **Overall Conclusion**

This review has demonstrated that educational interventions can successfully change staff attitudes towards older people's sexuality in residential care settings. An educational workshop format using a range of different methodologies can lead to statistically significant changes in attitudes towards sexuality. The conclusions drawn are limited in determining whether a change in attitude has led to change in practice and in determining the longevity of change in attitude. The small volume of literature in this area and the poor quality of some of the included studies limits the robustness of this review.

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## Exploring the Experiences of Providing Care at Home in Rural Areas for a Partner with Moderate to Severe Dementia: An Interpretative Phenomenological Analysis

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## PLAIN ENGLISH SUMMARY

### **Exploring the Experiences of Providing Care at Home in Rural Areas for a Partner with Moderate to Severe Dementia: An Interpretative Phenomenological Analysis**

**Background:** It is estimated that there are around 850,000 people in the United Kingdom living with dementia (Prince et al., 2014). Many individuals are cared for in nursing or care home settings, particularly in the later stages of the condition. However, two thirds of people with dementia remain cared for in their own home (O'Shaughnessy et al., 2010). Caregiving responsibilities usually fall to family members who may end up caring for an individual with dementia at home for many years. There is a shortage of studies which have looked at the experiences of relatives caring at home for a partner with moderate to severe dementia and the impact of living in rural locations on caregiving.

**Aims:** This study aimed to determine the lived experiences of caring at home for a partner in the later stages of dementia in rural populations. It focused on determining the experiences of coping, their needs and any other issues encountered.

**Methods:** Individuals (n=5) who were caring for a spouse or partner at home in rural areas with moderate to severe dementia were interviewed about their experiences. The semi-structured interviews were recorded and transcribed verbatim. The data was analysed using Interpretative Phenomenological Analysis.

**Results:** Four main themes emerged from the interviews: 1) changes in the spousal relationship; this theme explored commitment to the spousal relationship and the change in role; 2) the demands of caring, both the emotional demands and the magnitude of caring emerged from the interviews; 3) managing the demands, this theme focused on the support participant's receive from formal and informal sources and their own coping strategies; 4) unmet needs, the final theme explored unmet needs for the person with dementia, for carers and unmet needs related to rurality.

**Conclusion:** Participants described a range of experiences and it is hoped that a better understanding of this under researched population will help to provide information that will assist the development of future services. Suggested improvements included additional supports for carers to attend carers groups, increased continuity in community services and improved technology in rural areas.

## ABSTRACT

**Background:** The main body of literature investigating experiences of caring for a spouse with dementia has focussed on the experiences of receiving a diagnosis and on caring in the early stages of the disorder. The current study aimed to gain an in-depth understanding of caring for a spouse at home in rural areas with moderate to severe dementia.

**Method:** Semi-structured interviews were carried out with five participants who were caring for their partner at home in rural areas with moderate to severe dementia. Verbatim transcripts of the interviews were analysed using Interpretative Phenomenological Analysis (IPA).

**Results:** The analysis produced four superordinate themes; changes in the spousal relationship, the demands of caring, managing the demands and unmet needs.

**Conclusion:** Participants' accounts illustrated the complexity of caring for someone with moderate to severe dementia and the psychological and practical resources that are required in order to be able to continue to do so. Participants reflected on specific details of their romantic relationships, aspects of their situation and sources of support which facilitated them with the challenging task of caring.

**Key words:** *Dementia Carers, Rural, Severe Dementia, Spouse, Care at home*

## INTRODUCTION

It is estimated that there are around 850,000 people in the United Kingdom living with dementia (Prince et al., 2014). The number of people living with dementia worldwide is forecast to increase to over forty-two million by 2020 (Rizzi et al., 2014). Many people with dementia are cared for in residential settings, particularly in the later stages of the condition. However, two thirds of people with dementia remain cared for in their own home (O'Shaughnessy et al., 2010). Caregiving responsibilities typically fall to family members who may end up caring for an individual with dementia at home for many years. Family carers of people with dementia are estimated to save the United Kingdom £11 billion a year (Prince et al., 2014). Increases in the number of individuals living with dementia will not only impact on health services and resources but can also be expected to place significant responsibility and strain on family care-givers (Wimo et al., 2010).

The specific nature of dementia and its trajectory makes the context of care giving unique. People with dementia experience progressive physical and cognitive losses, which result in the person requiring increasing assistance from caregivers (Quinn et al., 2008). This can place cumulative stress, strain and burden on family carers (Etters et al., 2007; Gitlin et al., 2003; Cameron et al., 2011). Caregiver burden is defined as a “multi-dimensional response to the negative appraisal and perceived stress resulting from taking care of an ill individual” (Kim et al., 2011, pp. 846). The burden of caregiving is associated with reduced outcomes for caregivers such as illness, a reduction in their quality of life and depression (Schulz et al., 2006). This can have a negative impact on the care that they are able to provide and can also lead to poorer outcomes for recipients of care such as a poorer quality of life and early residential care placement (Gaugler et al., 2005).

Spouses face unique changes in their relationship when they care for a partner with dementia (O'Shaughnessy et al., 2010). Roles within the relationship may change, for

example a spouse will often become the main decision maker in the person with dementia's life and may be required to undertake unexpected responsibilities such as assisting with personal care tasks (Evans and Lee, 2014; Stolz et al., 2004.). As the person's dementia continues into the later stages of the condition the caregiver may experience a series of losses, which have been described as pre-death grief (Muders et al., 2015; Shanley et al. 2011). Spousal caregivers have reflected upon a gradual disconnect with their partner as the dementia progresses and the gradual loss of the person they knew (Peacock et al., 2016; Clipp and George, 1993).

Meeting the needs of people with dementia can pose challenges for caregivers. Such challenges may be compounded by the difficulties of providing and accessing services in rural areas (Innes et al., 2006). Aspects of rural living such as limited transportation and reduced access to health professionals and community-based programmes may all impact on care giving (Wertz et al., 2015). In comparison to the wider literature on experiences of caregiving, there is a relative lack of research on caregivers in remote and rural settings (Sun et al., 2010). A systematic review (Innes et al., 2011) concluded that, to date, research on family dementia care giving has focused on the barriers and experiences of accessing formal service provisions. The authors expressed a need for more research on the impact of rurality on care giving and the support needs of rural care- givers. The most recent Scottish Mental Health Strategy (The Scottish Government, 2017) has outlined a need to address the challenge of living in rural communities in order to reduce isolation and to ensure support is available to maintain good mental health and wellbeing.

There has been a focus in the literature to date on the experiences of the earlier stages of dementia, specifically on receiving a diagnosis (Bunn et al., 2012; Pratt and Wilkinson, 2003). Carers report that their experiences of caring for a spouse with the early stages of dementia include struggling to make sense of dementia and its impact on their relationship

with the care recipient, stress related to adjusting to these changes and a need to focus on coping day to day (Quinn et al., 2008). There is a relative lack of studies that have focused on the experiences of caring for a relative with moderate to severe dementia (Meuser and Marwitt, 2001).

Quantitative methodology has been criticized for its constraints in not allowing the subjective experiences of caregivers to be comprehensively captured (Lloyd et al., 2014).

Qualitative methodology allows a flexible approach to take into account carers' own views and gain a sense of their lived experiences and needs as a carer.

## AIMS

This study aimed to determine the lived experiences of caring at home in rural areas for a partner who has moderate to severe dementia. It focused on eliciting participants' experiences of coping in their situation, their experiences of accessing services and support, and any unmet needs they had.

## METHOD

### *Participants*

Individuals caring for their partner who was in the later stages of dementia were recruited across NHS Highland. Inclusion criteria specified that participants would be individuals who were caring for a spousal or long-term unmarried partner and were caring for a partner who was deemed to have moderate to severe dementia. A further inclusion criterion was that participants were living in rural areas of NHS Highland. Rurality was determined by those living in settlements of less than 3,000 people (The Scottish Government, 2012). Individuals who were not fluent in English; who had a cognitive impairment themselves; who lived in urban settlements or who were caring for a partner with young on-set dementia were not eligible for participation.

### *Sample size*

The study explored the experiences of caring within a homogeneous sample (caring for someone who is in the later stages of dementia and those living in a rural population). Smith et al. (2009) recommend a sample size of between four and ten interviews for doctoral level IPA research. Five participants were interviewed for the study. After analysis of interviews four and five it was determined that similar themes were emerging from the data and saturation of the data had potentially been reached. The focus in IPA research is on gaining detailed information on participants' experiences as opposed to a focus on the generalisability of data. Therefore this number of participants is anticipated to be able to generate sufficient insights to usefully explore the experiences of this specific sample.

### *Measures*

The Dementia Severity Rating Scale (DSRS) (Clark and Ewbank, 1996, provided in Appendix 10) was completed by carers and used as a screening to ensure the care-recipient was in the moderate to severe stages of dementia. A cut off score of 19 and above was used to determine the later stages of dementia, defined as moderately severe cognitive decline (Clark and Ewbank, 1996). The purpose of the DSRS (Clark and Ewbank, 1996) was as a screening measure to increase the robustness of the study, no demographic details were collected about the individual with dementia apart from the total score of the DSRS (Clark and Ewbank, 1996).

### *Ethics*

Prior to recruitment, the study was sent for proportionate review and was awarded a no opinion response due to concerns raised about the study not seeking permission from individuals who lacked capacity (the individuals with dementia). The study underwent further scrutiny from Scotland A Research Ethics Committee who specialise in this area and clarification was provided over the use of the DSRS (Clark and Ewbank, 1996). Approval was granted from the Committee and from NHS Highland Research and Development Department (Appendix 7). Participants were informed that participation in the study was voluntary and that they were free to withdraw from the study at any point in time without providing explanation. They were informed that this would have no impact on their current or future eligibility for access to services. Given the emotive content of the interviews participants were reminded that they could stop the interview at any point and all participants were provided with a resource sheet at the end of each interview which outlined contact details for sources of carer support.

### *Design*

The study used a qualitative design with semi-structured in-depth interviews. Interpretative phenomenological analysis (IPA) was used to analyse the interviews. IPA is concerned

with an individual's personal perception or experiences of an event (Smith et al., 1999). Its underpinnings include a focus on a determination to understand an individual's experience from their perspective, and its emphasis on dual hermeneutics, namely the researcher's efforts to make sense of the individual who is making sense of their own experiences. The approach allows for an in-depth exploration of individual experiences and therefore IPA was determined to be the most appropriate methodology to explore perceptions of providing care to a partner with dementia.

### *Recruitment*

Participants were recruited through the older adult Community Mental Health Teams (CMHT's) in NHS Highland. Clinicians were invited to review their caseloads in order to identify potential participants who met the inclusion criteria of the study. Prospective participants were provided with a participant information sheet about the study (provided in Appendix 8) and individuals who were interested in participating were asked to make contact with the researcher. The DSRS (Clark and Ewbank, 1996) was completed via telephone and eligibility for the study was ensured before a suitable time was arranged for interview.

### *Procedures*

At the time of meeting to conduct the interview, the researcher took informed written consent. Participants were interviewed on a one to one basis about their experiences of providing care at home to their partner. The interview schedule was semi-structured (see Appendix 9). Interviews were recorded on a digital voice recorder and transcribed verbatim. Interviews lasted between 51-57 minutes.

### *Reflexivity*

The researcher conducting the interviews was a trainee clinical psychologist completing a final year placement in an older adult CMHT, and therefore had some awareness of the challenges that carers can experience when caring for a person with dementia. This knowledge and experience may have influenced the interpretations that the researcher has made. A reflective diary was kept throughout the research process in order to monitor and note interpretations and reflections.

### *Data Analysis*

An IPA approach was used (Smith et al., 2009). Transcription and analysis of interviews began after the first interview had been completed in order to inform and make any necessary amendments to the interview schedule. After the interviews had been transcribed, the original transcripts were read and re-read in order to become familiar with the data. Transcripts were coded line-by-line (example excerpt provided in Appendix 12) and exploratory comments were noted before the emergent themes were developed. After this part of the analysis was completed, connections across cases were made, looking for patterns of emergent themes. An abridged table of themes is provided in Appendix 13. Finally, the researcher's own interpretation of the individuals' experiences were noted and incorporated into the final write up.

### *Sample characteristics*

Participants were four females and one male aged between 66-72. All participants were married to their partners. Four of the participants' spouses had a diagnosis of vascular dementia and one participant's spouse's diagnosis was unspecified. Scores on the dementia severity rating scale ranged from 20-44. The researcher travelled either to the participant's home (in three cases) or met at the participant's local G.P. surgery. Participants were recruited across three different CMHT'S in NHS Highland; approximate locations are shown in Figure 2.

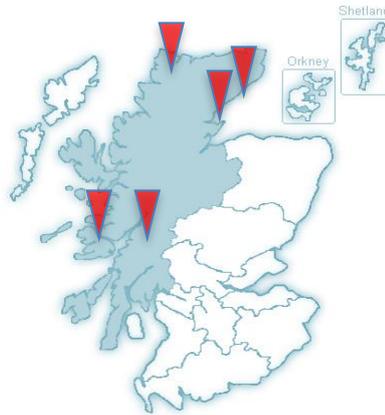


Figure 2. Approximate location of participants across NHS Highland.

## RESULTS

Four superordinate themes and ten interrelated sub-themes, which represent spousal experiences of providing care at home for a partner with moderate to severe dementia, emerged from the interviews and are summarised in Table 2.

Table 2: Summary of Themes

Superordinate themes	Subthemes
Spousal Relationship	<i>'I made a vow'</i> : Commitment to the relationship
	<i>'I'm more carer than wife'</i> : Change in role
Demands of Caring	<i>'I sit and cry, I break my heart'</i> : Emotional demands
	<i>'It's 24/7, day after day'</i> : Magnitude of caring
Managing the demands	<i>'You can't fault the support, help and advice'</i> : Formal sources of support
	<i>'Everybody in the village knows he has got dementia'</i> : Informal support
	<i>'I just let off steam'</i> : Coping strategies
Unmet needs	<i>'They are so short staffed'</i> : Resources for person with dementia
	<i>'They never got back to me'</i> : Resources for carers
	<i>'It's very isolating'</i> : Rurality

### THE SPOUSAL RELATIONSHIP

The first superordinate theme to emerge from participants' experiences of caring was the change they noticed in their spousal relationship. Two sub-themes emerged from participants' experiences: 1) commitment to the relationship and 2) a change in role.

#### **'I made a vow': Commitment to the relationship**

All five participants indicated that a sense of commitment to their relationship enabled them to take on the role of carer to their partner. Two participants related this to the

marriage vows they had taken, recognising the commitment that they had made to their partner:

*“ Yeah you just have to. It’s like with marriage you take your wedding vows, in sickness and in health, so I have to look after him.” (Peggy)*

Peggy’s description conveys a sense that she feels she has an obligation to care for her partner and her use of the word “have” twice within this extract indicates that she may feel that she has no choice in the matter. This could also be related to her own value base and her perception that a wife has a duty to care for their husband regardless of their health.

Jessica explained the positive changes that she has observed in her commitment to her relationship with her spouse since becoming a carer to him:

*“ I feel as though we were always very close anyway, we worked as a team but it’s, gosh, it’s cemented our relationship. You know I love caring for him...But now, with the dementia, I feel as though I love him far more.”*  
*(Jessica)*

This extract highlights the deep love and commitment that Jessica has for her partner and she explicitly states that the caring role and her husband’s diagnosis of dementia has added a further depth to her love for her husband. She conveys a strong, ever-lasting commitment by her use of the word ‘cemented’. Her comparison to the past indicates that she feels there

has been a change in the relationship with her husband albeit in her case, a significant positive change.

**‘I’m more carer than wife’: Change in role**

A change in role was evident throughout participants’ accounts. This was perhaps reflective of the severity of dementia in the individuals that they were caring for and the perceived shift of role from a romantic relationship to a caring one:

*“It’s going from wife to carer. It’s just I don’t know [pause] although lately I suppose I do feel I’m more like carer than a wife.... It’s just not the same at all.” (Peggy)*

This quotation from Peggy conveys the change she perceives in her relationship as she has moved from a romantic partner to a carer. She acknowledges the significance of the change by indicating that her relationship is not in anyway similar to how it was before. Hesitancy is apparent in Peggy’s discussion of this topic, which may suggest that this is a particularly emotive or difficult subject for her to discuss.

Four participants likened their experiences of caring for their spouse to caring for a child. Sarah indicated that her experiences of caring for her spouse were more difficult than caring for a child:

*“Auch it’s worse you know. At least with a toddler you can put the kid down and change it’s nappy and different things like that but this is different” (Sarah).*

This quotation appears to indicate that Sarah is feeling particularly helpless at her situation. Her account of caring for her husband may be suggestive of feelings that she does not have any strategies to appease him or make him more comfortable. With four out of the five participants comparing caring for a spouse to caring for a child, the change in role that has been described is strikingly clear. The majority of participants have described a shift from a romantic partner to a partner who is responsible for the complete care of an individual and likened this to the all-encompassing care of a child.

### **THE DEMANDS OF CARING**

The second superordinate theme to emerge from participant accounts is the demands of being a carer of someone with moderate to severe dementia. Two inter-related themes were extracted from the interviews; the emotional demands and the magnitude of caring.

#### **‘I sit and cry, I break my heart’: The emotional demands**

All of the participants in the study reflected on the emotions associated with being a spousal carer. Sarah describes the emotional impact of her experiences of caring:

*“I cry. I sit and cry, I break my heart... I’ve worked all of my life and now I’m sitting in and I’ve got this. I should be enjoying my retirement you know.” (Sarah)*

The depth of Sarah’s despair in relation to caring is apparent in this quotation. She describes a significant sadness about her situation and provides an appreciation of how challenging she finds her life as a carer. Her comparison to her working life gives a sense of her perception that her experiences of becoming a carer to someone with moderate to severe dementia are unjust and unfair. The phrase “I should be enjoying my retirement”

could indicate that Sarah feels an underlying degree of anger and resentment towards her husband for taking this away from her now that she is required to spend her time looking after him.

**‘It’s 24/7, day after day’: The magnitude of caring**

All of the participants were caring for a partner who was deemed to have moderate to severe dementia. Participants illustrated the high level of care that is required for someone at this stage of dementia throughout their accounts. Peter reflects on the multiple symptoms of dementia that impact on his experience of caring for someone at this stage of dementia:

*“ It’s not just a simple thing that they forget things. It’s all the other things that come along with it; the mood swings, the incontinence, everything you know, their health. It affects the whole being.” (Peter)*

Although progressive memory loss is perhaps the most frequently thought of difficulty associated with dementia, there are a number of other symptoms related to the disorder, particularly for those who are in the more moderate to severe stages. Peter’s description of dementia affecting ‘the whole being’ gives a sense of the comprehensiveness of the disorder and the complexity of dementia not just affecting memory. Three other participants also highlighted additional physical conditions that their spouse had and, although not directly related to dementia, they reflected on the impact that these conditions had on their experiences of caring.

When asked to describe her overall experience of caring, Isobel recounted:

*“Hellish. Is roughly how I would put it...it’s hard work  
and it’s twenty-four seven.” (Isobel)*

The use of the word ‘hellish’ is significant as it infers that nothing could be worse than Isobel’s experiences of being a carer. It is suggestive of caring being all encompassing and is reflective of the enormity of the level of care that she provides. It is a highly emotive word and may indicate that Isobel perceives her situation as helpless with no way out. Her use of the phrase twenty-four seven gives a sense of the relentless nature of caring and acknowledges that there is not one hour within the day where she feels she has a break from being a carer. Isobel directly addresses the magnitude of support that is required when caring for an individual with dementia at home.

## **MANAGING THE DEMANDS**

As has been illustrated throughout the participant accounts, caring can be an extremely challenging endeavour psychologically, physically and practically. The third superordinate theme focuses on the resources that carers draw upon to assist them to continue to care at home for their partner. Three sub-themes emerged from participants’ accounts: 1) formal sources of support, 2) informal sources of support and 3) carers’ own coping strategies.

### **‘You can’t fault the support, help and advice’: Formal sources of support**

All five participants provided at least one example of positive experiences of formal sources of support, such as NHS services or carer groups, which led them to feel well supported as a carer:

*“If I ever wanted to know something or wasn’t sure about something she [CPN] was always there at the end of the phone... It’s ok really because none of them can cure him.”*

*(Jessica)*

Jessica’s words indicate that she feels a strong sense of support specifically from formal sources and in her case a community mental health nurse. There is a suggestion that the feeling of having someone who she could access at any point in time gave her a sense of security and confidence in her abilities to care. Her acknowledgement at the end of this extract that sources of help can provide support only and will not cure her husband is poignant.

Peter had similar levels of praise for formal supports that he had accessed:

*“You can’t fault the support and help and advice and information you know” (Peter)*

#### **‘Everybody in the village knows he has got dementia’: Local sources of support**

One of the aims of this study was to determine the impact on caring of living in rural areas. All of the participants indicated that they felt living in a rural area allowed them to care either just as well or made caring easier in comparison to hypothetically living in an urban area. The main factor participants’ cited for this was the high level of informal local support provided to them in close-knit rural communities:

*“I think in some ways I might be better off than people living in a town because everyone knows us because we’ve lived in the area*

*for so long and just people that are acquaintances I know if need  
be they would drop whatever they were doing and help us.”*

*(Jessica)*

Jessica draws attention to the fact she perceives living in a rural area gives her an advantage over those living in more urban areas. She acknowledges that within the close-knit community she feels that it would be people who she refers to as ‘acquaintances’ that would provide her with support suggesting that she feels supported by a wide, perhaps informal community. Her indication that people would ‘drop whatever they were doing’ gives a sense of the immediacy with which she feels help can be provided and the priority that she is given from the rural community.

#### **‘I just let off steam’: Coping strategies**

Personality characteristics, distraction techniques and time alone emerged from participant accounts as personal coping strategies that are relied upon to help with the stress of caring for their spouse. Peggy reflects upon one of her coping strategies:

*“I go off in the car, I drive somewhere, have a rant and  
when I’ve calmed down I’ll go back.” (Peggy)*

This extract illustrates Peggy’s desire to have some time alone, away from her spouse to reduce her arousal levels. Interestingly Peggy goes in the car for a drive perhaps indicating that she perceives the need for further space and distance from her spouse and the home environment. Throughout her account Peggy spoke of the frustration she feels at the repetitive questions her husband asks as a result of his memory impairment and the strategy she describes may be one way in which she manages her levels of frustration at this

symptom of dementia. Peggy's words provide an insight into the relentless nature of caring for someone at home and her strategy of managing the stress that comes with this.

## **UNMET NEEDS**

There were several instances in participants' accounts where they expressed feelings of being well supported in their caring journey but there were also examples where participants described their needs as not having been met. The fourth superordinate theme highlights three sub-themes which emerged of unmet needs: 1) resources for the individual with dementia, 2) resources for carers and 3) rurality.

### **'They are so short staffed': Resources for person with dementia**

The first sub-theme captured instances where participants spoke of the limitations or dissatisfaction with regards to services for the individual with dementia. Three participants spoke specifically about NHS resources being under resourced:

*"He [NHS care worker] used to come one day a week but he's changed it to, I think he's got so much on his plate, and he comes once every 2 weeks."(Peggy)*

Peggy speaks about a member of the CMHT who provides one to one support to her husband. She spoke highly of this input in her account both for her and her husband, however, she reflects on the reduction in frequency of this support. Her use of the words 'he's got so much on his plate' suggests that Peggy has perhaps picked up on the pressure that NHS staff members are under and she has identified a wider issue of a current lack of resource within the NHS. It may also tap into a cohort belief shared by older people of a

sense of gratefulness of any service that the NHS can offer, perhaps born out of a time prior to free healthcare.

### **‘They never got back to me’: Resources for carers**

Unmet needs in relation to carer resources were also mentioned throughout participant accounts. The challenges and limitations of respite care and carer support groups were each mentioned by all five participants. Four participants reflected on the challenges of attending carers groups:

*“If I went to a carers group then I’d have to take him with me or then pay again for someone to sit with him while I go to the group to sit with people and think, well this doesn’t really apply to me.” (Isobel).*

Isobel highlights some of the issues that have prevented her from seeking formal support from a carers group. She explains that there are financial considerations to caring which she needs to take into account, as she would be required to pay for a formal source of support to look after her husband whilst she attended a carers group. Her quotation is also suggestive of discontent at the group itself where she perceives the support is not applicable or individualised to her own needs.

Isobel provides a further insight into instances where her needs as a carer have not been met:

*“But yes when he had a bad fall and hit his head off there and cracked it open, nobody turned round and said how are you?  
Or we’ll give you a check you know... that last lot of*

*paramedics were the only ones that ever asked me how I was  
you know, was I alright?” (Isobel)*

Isobel’s words provide an insight into her feelings of the lack of support that she is provided with as a carer. In her account she described frequent instances of visits from health professionals to her house, as her husband’s poor mobility now makes it difficult for him to leave the house. This extract gives an understanding of a relatively straightforward manner in which she perceives that care from health professionals could be improved. Simply checking in with carers and asking how they are coping may be of significant benefit to the carer.

**‘It’s very isolating’: Rurality**

Although all participants spoke of their fondness of living in a rural area and reported that they perceived living in a rural area to be beneficial for them to care, two participants spoke of the poor transport links in their area and the impact that this has on them as carers:

*“I’m definitely isolated.” (Sarah)*

Sarah described dissatisfaction with the public transport links in the rural area that she lived in. She also reflected on the impact of her own physical health concerns that made taking public transport an arduous task for her. A combination of these factors has resulted in Sarah feeling a sense of isolation and she described the knock-on effect this has on other aspects of her caring experience such as being unable to access carer support groups and being unable to leave the house to have time for herself.

Three of the participants in this study discussed concerns about their partner wandering. Jessica provides a unique insight into one of the challenges of caring for a person with moderate to severe dementia in a rural area:

*“Because we have no mobile reception we can’t use  
the GPS tracker.”(Jessica)*

Jessica highlights a practical concern of caring for an individual with moderate to severe dementia in rural areas. She acknowledges a limitation of residing in a rural area where there is no mobile reception, which has resulted in her being unable to use GPS technology to track her husband when he wanders.

## DISCUSSION

This study sought to understand the unique experiences of caring at home in rural areas for a spouse with moderate to severe dementia. Although each individual's experience was unique, certain commonalities emerged from the data. Four superordinate themes emerged from the analysis: changes in the spousal relationship; the demands of caring; managing the demands and unmet needs.

### **Key findings**

#### **The spousal relationship**

All five of the participants in the study commented on their spousal relationships as they have taken on the role of carer. Consistent with previous research, couples experienced a persistent commitment to their marriage in spite of a diagnosis of dementia (Davies, 2011). A change in role emerged from the interviews as participants navigated the shift from spouse to carer. O' Shaughnessy et al. (2010) conceptualised changes in the spousal relationship in dementia care from that of an equal partner to one of increasing dependency. The findings from this study determine that despite caring for someone at the moderate to severe stages of dementia, and perhaps being a carer for several years, spousal carers continue to contemplate and evaluate the change in their relationship status.

#### **The demands of caring**

The magnitude of caring for a person with moderate to severe dementia was apparent across participant accounts. Carers reflected on the multiple difficulties that are associated with the disorder that go above and beyond memory loss. They described the intense physical effort that was required to provide care whilst acknowledging the limitations of their own physicality. Individuals within this study described their experiences of caring in a passionate, emotive manner both through their descriptions and by expressed emotion in the interviews. Emotional strain has been determined to be an independent risk factor for

mortality amongst older, spousal caregivers (Schulz and Beach, 1999). Therefore, the importance of determining which resources carers draw on to cope with the emotional demands of caring is imperative.

### **Managing the demands of caring**

Carers described a range of different support systems to help them cope with the demands of being a carer including formal sources of support and their own personal coping strategies such as self-care. However, the most significant support mentioned was informal sources from close-knit communities. This finding is in contrast to previous research, which found little evidence to either support or refute the benefits of a close-knit community when caring (Orpin et al., 2014).

Lazarus and Folkman's (1984) transactional model of stress and coping is one of the most frequently discussed stress adaption models. Haley et al. (1987) proposed an adapted version of the model for caregiving. In their framework, carers' appraisal of the stress, their available coping strategies and social support were identified as mediating factors on the effect of caregiving stress on wellbeing. When considering the results of this study in context of this framework, the significance of social supports for carers is apparent. Four out of five participants in this study spoke of the benefits of community social support and related this to residing in a rural area. Further investigation of the similarities and differences between social supports in rural and urban areas is warranted.

### **Unmet needs**

Unmet needs for carers, care-recipients and in respect to rurality were alluded to throughout participant accounts. Areas of note included the difficulties in accessing carer support groups, services being under-resourced and poor transport links in rural areas. Perhaps related to the severity of dementia of the spouses, participants' spoke of the

challenges of leaving their spouse at home in order to attend carer support groups. This is potentially an exclusive challenge for those caring for someone in the moderate to severe stages of dementia given the additional supervision of the individual that is required. Future services may benefit from providing additional supports, such as care for their spouse, in order for carers to access support systems such as carer groups.

Three participants discussed limitations of formal services that they had accessed such as a lack of follow up contact and a reduction in frequency of services. Toot et al. (2013) determined the leading cause of crises in dementia care to be poor and inadequate community services, including poor continuity of care. Although there is currently a significant financial pressure on NHS services, investment in adequate services that can provide continual support will help to reduce crises in dementia care and may ultimately help to reduce overall costs of care. There is currently a significant financial pressure within the NHS and limited resource for additional services therefore it is important to consider the efficacy of existing services to ensure continuity of care. Suggestions from the results of this study include carers and individuals with dementia having flexibility of when they make use of their one year of post diagnostic support, perhaps delaying or splitting some of the time for support in the moderate to severe stages of the condition. A further recommendation from participants of this study is ensuring that all members of the multi-disciplinary team enquire about carer wellbeing when they have contact with an individual with dementia.

Although Jessica was the only participant to pick up on the shortcomings of mobile reception in rural areas, it is an important consideration to take into account given that three participants expressed concerns about wandering, and the advances in technology in dementia care specifically for individuals continuing to reside at home in the moderate to severe stages of dementia (Landau et al., 2009).

### **Methodological strengths and limitations**

This study focussed on the experiences of a specific sample of individuals. Participants who were selected for interview for the study were all providing care for their spouse at home and a screening tool, the Dementia Severity Scale (Clark and Ewbank, 1996), was used to ensure that participants were caring for a spouse who had moderate to severe dementia. An additional strength is the focus solely on spousal relationships where previous carer studies have often included both spousal and parent-child carers (Gilliam and Steffen, 2005). These steps have attempted to ensure that a homogenous sample have been selected for the study and for this specific sample of spousal carers' experiences to be represented.

This study had a small sample size of five participants. A strength of qualitative research and particularly IPA is the in-depth analysis of participants' lived experiences. It allows for a comprehensive analysis of subjective experiences. However, a limitation of this methodology is that the experiences are restricted in their generalisability to a larger population.

Some of the reflections noted by the researcher that may have impacted on the interviews included the researcher and research materials being affiliated with the NHS and therefore there may have been reluctance from participants to recount their thoughts about NHS services and provisions. An additional consideration was the age gap between the researcher and the participants. Positively, participants appear to have been open in their reflections and have discussed poignant, emotive subjects with the researcher.

### **Implications for clinical practice**

This study has illustrated areas where practice appears to be working well and carers are reportedly feeling well supported. Participants in the study appeared to appreciate contact with health professionals where they felt support could be provided quickly if requested. An individual expressed the discontent she felt when health professionals visiting her spouse did not enquire as to how she was coping. This is a relatively simple request that could be incorporated into a standard protocol for occasions when a person with dementia is being assessed or treated.

Given the 'just get on with it' stoic attitude that can be apparent at times in older people, it may be necessary to proactively identify carers who may potentially be at risk of increased stress due to some of the factors extracted from this study such as a lack of informal supports, difficulties in accessing appropriate transport and reduced physical abilities of the carer. Carers' needs should be assessed regularly at different points in their caregiving journey given that their needs may change and evolve (Novais et al., 2017).

### **Future research**

The majority of participants in this study reported that they felt living in a rural location assisted them with their caring duties. This was a result of the significant sense of support they felt they received from the close-knit rural communities. Many participants in this study reflected that they would predict living in an urban city would make caring more difficult. It would be interesting for a comparison qualitative study to be conducted with carers who are caring for spouses who had moderate to severe dementia but were living in urban areas. This would enrich the literature by determining whether sources of informal support are unique to rural settings or whether they are apparent in urban settings as well.

The focus of this study was on carers in an attempt to understand their experiences and although the participants made frequent reference to the person with dementia that they

were caring for, no direct data was collected from the individuals with dementia. Although there may be challenges and ethical constraints of conducting research with participants who lack capacity a suggestion for future research is to gather the views of individuals with moderate to severe dementia who are being cared for. The challenges should not limit research being conducted with this population and it would ensure that the views of this marginalised group of people in society are heard and respected.

## **Conclusions**

This study explored the experiences of individuals who are providing care at home in rural areas to their partners with moderate to severe dementia. Participants' accounts illustrated the complexity of caring for someone with moderate to severe dementia and the psychological and practical resources that are required in order to be able to continue to do so. Participants reflected on specific details of their romantic relationships, aspects of their situation and sources of support which facilitated them with the challenging task of caring. Possible areas for future research were discussed.

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## APPENDICES

### Appendix 1

#### Instructions for Authors

The manuscript text and references should be double-spaced with 1-inch margins. The body of the text should be between 4,000 and 6,000 words, although longer articles occasionally will be published.

Brief research reports, commentaries, or practice reviews of 1,000 to 2,000 words are also welcome.

An abstract of up to 150 words should be included with all submissions.

Authors who wish to have their manuscripts considered as a highlighted mixed method, translational, or process evaluation study should indicate this in a cover letter to the Editor-in-Chief.

To facilitate blind review, manuscripts and abstracts with no identifiers should be accompanied by a cover sheet with title, author(s), and affiliations(s), including complete mailing and e-mail address(es).

The format outlined in the Publication Manual of the American Psychological Association (6th edition) should be employed. Manuscripts submitted will be reviewed initially by the Editor for conformance to page limitations and for content appropriate for blind review.

Manuscripts accepted for publication are subject to stylistic editing with the edited draft sent to the corresponding author for final review.

It is the author's responsibility to disclose any potential conflict of interest regarding the manuscript on their title page. Authors will be required to fill out financial disclosure information and sign an exclusive licensee agreement upon acceptance of a manuscript. Any conflict or financial disclosure will be published within the manuscript.

Any identifying information regarding a patient should be removed from the manuscript or informed consent from the patient will be required.

Manuscripts must identify their IRB protocol number/human subjects approval numbers on the title page. Upon submission, papers are checked to ensure that they include this identifying information.

## Appendix 2.

### Search Terms

Database	Search Terms	Results	Date searched
<b>MEDLINE</b> <b>AND</b> <b>EMBASE</b>	1. exp attitude/ or exp "attitude of health personnel"/  2. attitude*.af.  3. (belief* or knowledge or perspective* or opinion*).af.  4. 1 or 2 or 3  5. exp Homes for the Aged/  6. "home\$ for the aged".af.  7. "nursing home\$".af.  8. "care home\$".af.  9. "old age home\$".af.  10. "residential homes\$".af.  11. 5 or 6 or 7 or 8 or 9 or 10  12. 4 and 11  13. sexual*.af.  14. 12 and 13	190	9 <sup>th</sup> April 2017
<b>CINHAL &amp;</b> <b>PSYCHINFO</b>	S11 S7 AND S10 S10 S8 OR S9 S9 sexual* S8 (MH "Sexuality+") OR "sexuality" OR (MH "Attitude to Sexuality+") S7 S5 AND S6	242	9 <sup>th</sup> April 2017

	<p>S6 (MH "Long Term Care") OR "long term care" OR (MH "Nursing Home Patients") OR (MH "Residential Care+")</p> <p>S5 S3 OR S4</p> <p>S4 belief* OR knowledge* OR perspective* OR opinion*</p> <p>S3 S1 OR S2</p> <p>S2 (MH "Attitude+") OR "attitude" OR (MH "Attitude to Sexuality+")</p> <p>S1 ATTITUDE*</p>		
<b>WEB OF SCIENCE</b>	<p>#7 #6 AND #5</p> <p>#6 TS=(sexual*)</p> <p>#5 #4 AND #3</p> <p>#4 TS=("nurs* home" OR "care home" OR "residential home" OR "home for the aged" OR "long term care")</p> <p>#3 #2 OR #1</p> <p>#2 TS=(belief* OR opinion* OR knowledge* OR perspective*)</p> <p>#1 TS=(attitude*)</p>	182	10 <sup>th</sup> April 2017
<b>ETHOS</b>		87	11 <sup>th</sup> April 2017

## Appendix 3

# Data extraction form

### Study characteristics

Year:

Country:

Study purpose or aims:

Study inclusion criteria:

Study exclusion criteria:

### Participant characteristics (staff)

Age range =

Gender =

Education =

Job role=

### Characteristics of older people

Age range =

Gender =

Setting=

Description of dementia/ non dementia =

### Recruitment

How were participants recruited?

**Measure**

What measure was used to determine attitudes?

**Intervention**

Description of intervention used to shift attitudes

**Results**

Results/conclusion of the study

Statistical Analysis

Strengths / Weaknesses of the study

Quality rating \_\_\_\_\_

## Appendix 4

Downs & Black, (1998) Adapted Quality Rating Scale

Question number	Question	Rating scores	Score
<b>Abstract/Introduction</b>			
1.0	Does the abstract give a structured summary of the study?	Yes=2 Partially=1 No =0	
1.1	Has a scientific background and justified rationale been provided?	Yes=2 Partially=1 No =0	
1.2	Are the hypothesis / aim/ objective of the study clearly described?	Yes=2 Partially=1 No =0	
1.3	Are the main outcomes to be measured clearly described in the introduction or methods section?	Yes=2 Partially=1 No =0	
<b>Participants</b>			
2.0	Are the characteristics of the participants (staff) included in the study clearly described?	Yes=2 Partially=1 No =0	
2.1	Are the characteristics of the subjects (older people) clearly described?	Yes=2 Partially=1 No =0	
2.2	In studies with a control group were subjects randomised to each group	Yes=2 Partially=1 No/No control group =0	
2.3	Were subjects representative of the population?	Yes=2 Partially=1 No/unclear =0	
2.4	Is the level of drop-out described and were adequate attempts made to explore reasons for drop-out?	Yes=2 Partially=1 No =0	
<b>Intervention</b>			
3.0	Is the intervention to shift attitudes clearly described?	Yes=2 Partially=1 No =0	
3.1	Was compliance with the intervention reliable?	Yes=2 Partially=1 No =0	

3.2	Were the main outcome measures used accurate (reliable and valid)?	Yes=2 Partially=1 No =0	
Results			
4.0	Are main confounding variables taken into consideration?	Yes=2 Partially=1 No/unclear =0	
4.1	Are the main findings of the study clearly described?	Yes=2 Partially=1 No =0	
4.2	Are confidence intervals/ effect sizes etc. reported where appropriate?	Yes=2 Partially=1 No =0	
4.3	Were the statistical tests used to assess the main outcomes appropriate?	Yes=2 Partially=1 No =0	
Discussion			
5.0	Do the conclusions drawn directly link to the results?	Yes=2 Partially=1 No =0	
5.1	Are the limitations of the study discussed?	Yes=2 Partially=1 No =0	
Total score			

Overall quality rating Good  
Moderate  
Poor

## Appendix 5

### Quality item ratings for each study

Question	1.0	1.1	1.2	1.3	2.0	2.1	2.2	2.3	2.4	3.0	3.1	3.2	4.0	4.1	4.2	4.3	5.0	5.1	Total	Overall	
Study																					Rating
Aja & Self (1986)	1	2	2	1	2	0	2	2	2	2	2	2	1	2	1	2	2	0	28	Good	
Bauer et al (2013)	1	2	2	2	2	0	0	2	1	2	1	2	2	2	2	2	2	2	29	Good	
	(1)	(2)	(2)	(2)	(2)	(1)	(0)	(1)	(0)	(2)	(2)	(2)	(2)	(2)	(2)	(2)	(2)	(2)	[30]		
						[0]		[2]			[2]										
Livni (1984)	1	1	2	2	1	0	0	2	0	2	2	1	2	2	2	2	2	0	24	Adequate	
Stinke (1997)	1	2	1	2	2	0	0	2	1	1	2	2	0	2	1	2	2	2	25	Adequate	
	(1)	(2)	(1)	(2)	(2)	(0)	(0)	(1)	(0)	(2)	(2)	(2)	(0)	(2)	(1)	(2)	(2)	(2)			
								[2]	[1]												
West (1983)	1	0	1	0	0	0	0	1	0	2	0	0	0	1	0	0	1	0	7	Poor	
Walker & Harrington (2010)	1	2	1	2	2	0	0	2	0	1	1	1	1	2	0	2	2	2	22	Adequate	
	(1)	(2)	(1)	(2)	(2)	(0)	(0)	(1)	(0)	(1)	(1)	(2)	(2)	(2)	(1)	(2)	(2)	(2)	[23]		

								[2]					[1]		[0]						
White & Catania (1982)	1	2	2	2	1	0	2	2	0	2	1	2	1	2	2	2	2	2	1	27	Good
Jones & Moyle (2016)	1	2	2	2	2	0	0	2	0	2	2	2	2	2	0	2	2	2	27	Good	
	(1)	(2)	(2)	(2)	(2)	(0)	(0)	(2)	(1)	(2)	(2)	(2)	(2)	(2)	(0)	(2)	(2)	(2)			
									[0]												
Reingold & Burros (2004)	1	1	0	0	1	0	0	1	0	1	1	0	0	0	0	0	0	0	6	Poor	
	(1)	(0)	(1)	(0)	(0)	(0)	(0)	(0)	(0)	(0)	(0)	(0)	(0)	(0)	(0)	(0)	(0)	(0)	[4]		
		[0]	[0]		[0]			[1]		[1]	[1]										
Mayer & McBride (1998)	1	0	1	1	2	0	0	1	0	2	0	0	0	2	0	0	1	0	11	Poor	

**Key**

(number) = ratings of second researcher

[number] = agreed ratings



## Appendix 6

### Aging and Mental Health Author Guidelines

If your article is accepted for publication, the manuscript will be copyedited and typeset in the correct style for the journal.

**Font:** Times New Roman, 12 point, double-line spaced. Use margins of at least 2.5 cm (or 1 inch). Guidance on how to insert special characters, accents and diacritics is available [here](#).

**Title:** Use bold for your article title, with an initial capital letter for any proper nouns.

**Abstract:** Indicate the abstract paragraph with a heading or by reducing the font size. Check whether the journal requires a structured abstract or graphical abstract by reading the Instructions for Authors. The Instructions for Authors may also give word limits for your abstract. Advice on writing abstracts is available [here](#).

**Keywords:** Please provide keywords to help readers find your article. If the Instructions for Authors do not give a number of keywords to provide, please give five or six. Advice on selecting suitable keywords is available [here](#).

**Headings:** Please indicate the level of the section headings in your article:

1. First-level headings (e.g. Introduction, Conclusion) should be in bold, with an initial capital letter for any proper nouns.
2. Second-level headings should be in bold italics, with an initial capital letter for any proper nouns.
3. Third-level headings should be in italics, with an initial capital letter for any proper nouns.
4. Fourth-level headings should be in bold italics, at the beginning of a paragraph. The text follows immediately after a full stop (full point) or other punctuation mark.
5. Fifth-level headings should be in italics, at the beginning of a paragraph. The text follows immediately after a full stop (full point) or other punctuation mark.

**Tables and figures:** Indicate in the text where the tables and figures should appear, for example by inserting [Table 1 near here]. The actual tables should be supplied either at the end of the text or in a separate file. The actual figures should be supplied as separate files. The journal Editor's preference will be detailed in the Instructions for Authors or in the guidance on the submission system. Ensure you have permission to use any tables or figures you are reproducing from another source.

- Advice on obtaining permission for third party material is available [here](#).
- Advice on preparation of artwork is available [here](#).
- Advice on tables is available [here](#).

**Running heads** and **received dates** are not required when submitting a manuscript for review; they will be added during the production process.

**Spelling and punctuation:** Each journal will have a preference for spelling and punctuation, which is detailed in the Instructions for Authors. Please ensure whichever spelling and punctuation style you use is applied consistently.

## Appendix 7

Miss Emily Boyd  
Drumossie Unit  
New Craigs Hospital  
Leachkin Road  
Inverness  
IV3 8NP  
5678  
March 2017

**Scotland A REC**  
Waverley Gate  
2-4 Waterloo Place  
Edinburgh  
EH1 3EG  
Telephone: 0131 465

Dear Miss Boyd,

**Study title: A qualitative study on the experience of spouses providing care at home in rural locations for a partner with dementia**

**REC reference: 17/SS/0006**

**IRAS project ID: 20751**

Thank you for your letter of 06 March 2017 I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 06 March 2017

### Documents received

The documents received were as follows:

### Approved documents

The final list of approved documentation for the study is therefore as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Email to potential JDR participants]	2	30 September 2016
Covering letter on headed paper	1	22 November 2016
Covering letter on headed paper [Covering letter]	2	06 March 2017
Interview schedules or topic guides for participants [Interview Schedule]	2	06 March 2017
IRAS Checklist XML [Checklist_07032017]		07 March 2017
Letter from funder [Proceed to ethics letter - T M McMillan]	1	19 May 2016
Letters of invitation to participant [Invitation letter]	3	06 March 2017
Other [Resource Sheet]	1	25 July 2016
Other [Proposal feedback from reviewers]	1	22 February 2016
Other [Health and safety protocol]	4	06 March 2017
Participant consent form [Consent Form]	2	06 March 2017
Participant consent form [Consent to be contacted]	3	06 March 2017

Participant information sheet (PIS) [Participant Information Sheet]	3	06 March 2017
REC Application Form	207519/1 034072/1/ 760	02 December 2016
Research protocol or project proposal [Proposal]	5	06 March 2017
Summary CV for Chief Investigator (CI) [- Emily Boyd]	1	25 July 2016
Summary CV for supervisor (student research)	2	22 July 2016
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Plain English Summary]	2	06 March 2017
Validated questionnaire [Dementia Severity Rating Scale]	2	01 April 1996

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

<b>17/SS/0006</b>	<b>Please quote this number on all correspondence</b>
-------------------	---

Yours sincerely,



**Chloe Eves**  
**Research Admin Officer**

E-mail: [chloe.eves@nhslothian.scot.nhs.uk](mailto:chloe.eves@nhslothian.scot.nhs.uk)

Copy to: *Ms Frances Hines, NHS Highland*

**Professor Angus Watson**  
Research, Development & Innovation Director  
Research, Development & Innovation Division  
NHS Highland  
Centre for Health Science  
Old Perth Road  
Inverness  
IV2 3JH



Tel: 01463 255822  
Fax: 01463 255838  
E-mail: angus.watson@nhs.net

06 April 2017

NHS Highland R&D ID: **1328**  
NRSPCC ID: **NA**

Ms Emily Boyd  
Trainee Clinical Psychologist  
Drumossie Unit  
New Craigs Hospital  
Leachkin Road  
Inverness  
IV3 8NP

Dear Ms Boyd,

**Management Approval for Non-Commercial Research**

I am pleased to tell you that you now have Management Approval for the research project entitled: **'A Qualitative Study on the Experience of Spouses Providing Care at Home in Rural Locations for a Partner with Dementia'**. [Protocol V5 06/03/17]. I acknowledge that:

- The project is sponsored by the University of Glasgow.
- The project does not require external funding.
- Research Ethics approval for the project has been obtained from the Scotland A Research Ethics Committee (Reference Number: 17/SS/0006).
- The project is Site-Specific Assessment exempt.

The following conditions apply:

- The responsibility for monitoring and auditing this project lies with the University of Glasgow.
- This study will be subject to ongoing monitoring for Research Governance purposes and may be audited to ensure compliance with the Research Governance



**Headquarters:**  
NHS Highland, Assynt House, Beechwood Park, Inverness, IV2 3HG

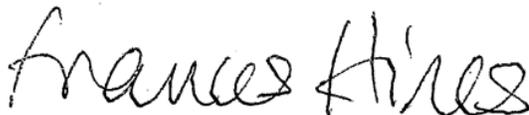
Chairman: David Alston  
Chief Executive: Elaine Mead

Framework for Health and Community Care in Scotland (2006, 2<sup>nd</sup> Edition), however prior written notice of audit will be given.

- You are reminded that all amendments (minor or substantial) to the protocol and associated study documents or to the REC application should be copied to the NHS Highland Research and Development Office together with a copy of the corresponding approval letter. Guidance can be found at <https://www.nhsresearchscotland.org.uk/services/permissions-co-ordinating-centre/permissions>
- The paperwork concerning all incidents, adverse events and serious adverse events, thought to be attributable to participant's involvement in this project should be copied to the NHS Highland R&D Office. Please email documents to Anna Skene, RD&I Facilitator ([anna.skene@nhs.net](mailto:anna.skene@nhs.net)).
- If applicable, monthly recruitment rates should be notified to the NHS Highland Research and Development Office, detailing date of recruitment and the participant trial ID number. This should be done by e-mail on the first week of the following month, to Debbie McDonald, RD&I Data Manager ([debbie.mcdonald@nhs.net](mailto:debbie.mcdonald@nhs.net)).
- Please report any other changes in resources used, or staff involved in the project, to the NHS Highland Research and Development Manager, Frances Hines (01463 255822, [frances.hines@nhs.net](mailto:frances.hines@nhs.net)).

*Please quote your RD&I Highland reference number (Highland 1328).*

Yours sincerely,



Frances Hines  
RD&I Manager

cc [Frances Hines](#), R&D Manager, NHS Highland Research, Development & Innovation Division, Phase 3, The Centre for Health Science, Old Perth Road, Inverness, IV2 3JH

## Appendix 8

### Participant Information Sheet

#### Introduction

My name is Emily Boyd, and I am a Trainee Clinical Psychologist at the University of Glasgow. You have been given this information sheet because you are being invited to take part in my final year research project, which will be submitted as a part of my Doctorate in Clinical Psychology. The project is supervised by Dr Sue Turnbull; University Teacher, University of Glasgow and Dr Andrew MacDougall; Consultant Clinical Psychologist, NHS Highland.

#### Title of study

A qualitative study on the experiences of providing care at home in rural locations for a partner with dementia.

#### What is the purpose of the study?

I am interested in finding out about your experiences of caring at home for your partner. I am interested in hearing about your experiences, your coping strategies, your needs and any other issues that you have encountered. It is hoped that this study may provide information that will identify any unmet needs and may assist in contributing to the development of future services.

#### Why have I been chosen as a potential participant?

You have been given this information sheet because you are currently caring at home for a partner who has moderate to severe dementia. I am also interested in the impact of rurality on caregiving and so I am interested in hearing about your experiences as you are living in an area that is deemed to be rural.

#### Do I have to take part?

No. Participation in the study is entirely voluntary; you do not have to take part if you do not wish to. The services that you currently access or may access in the future will not be affected in any way if you choose not to take part in the study. You are also free to withdraw from participation in the study at any point. You do not have to provide a reason for doing so. You may also request that any information you have provided is withdrawn from the study.

#### What will happen if I choose to take part?

If you decide you would like to take part in the study, please contact me to express interest either by email: [e.boyd.1@research.gla.ac.uk](mailto:e.boyd.1@research.gla.ac.uk), by telephone: 01463 253697 or by completing the consent to be contacted form included (Version 2, 06/03/17) and posting it back to me in the included envelope. I will then telephone you to discuss the study further. In this telephone call I will administer the Dementia Severity Rating

Scale (Clark & Ewbank, 1996). This questionnaire is provided in this study pack for your information but you do not have to complete it prior to the telephone call. If you meet the inclusion criteria for the study we will then arrange a suitable time to meet for the interview. This will either be at your G.P. surgery or at a local health centre convenient to you. If it would be difficult for you to attend one of these premises but you still wish to take part in the study, please contact me to discuss alternative options. When we meet, I will ask you to read and sign the consent form (Version 2, 06/03/17) to confirm that you understand what is involved by agreeing to take part in the study and that you wish to proceed. The interview will last for no more than one hour. I will record the interview using an encrypted digital voice recorder to make sure that I have an accurate record of what we have talked about.

### **Are there any down sides to taking part in the study?**

You may find it difficult discussing some of your experiences related to caring at home for your partner. You may take a break or request to stop the interview at any point if you choose to do so. You will be provided with a resource sheet at the time of interview, which contains information about services that you can access providing support for carers.

### **Are there any benefits of taking part in the study?**

There are no direct benefits to you in taking part in this study. The findings of this study may provide information that will assist the development of future services and identify any needs which are currently unmet. The results of the study may also provide suggestions for further research.

### **Will my information remain confidential?**

The information that you provide as part of the study will remain confidential. The only people who will have access to this information will be myself, the academic supervisor (Dr Sue Turnbull) and the field supervisor (Dr Andrew MacDougall). Representatives of the study sponsor, NHS Highland, may also have access to your information to make sure the study is being conducted properly. A report will be written that may use quotations that you have provided within the interview but any identifiable information you have provided such as names of people or places will be removed. If I felt that there was anything that we discussed in the interview that was a risk to yourself or to someone else then I would be required to break confidentiality. I would have a discussion with you to explain why I felt it was necessary to break confidentiality.

### **What will happen to my information?**

The information from your interview will be transcribed word for word. I will give your transcript a code so that it cannot be linked back to your name and I will remove any identifiable places or people's names. Quotations of what you have said in the interview may be used in the write up of the study. The study will be written up and submitted as part of my Doctorate in Clinical Psychology. A summary document of the results will be provided to participants who have requested it. The results will also be submitted for publication in a scientific journal and may be presented at conferences. Following your interview, the recording will be kept in a locked cabinet in NHS Highland premises. After the interview has been transcribed it will be deleted from the encrypted digital recorder. Another individual also conducting qualitative

research will check a sample of the transcripts for accuracy. Your interview transcript will be stored on a secure password protected laptop and then backed up on a University of Glasgow desktop computer. Data will be held securely for a period of ten years after the completion of the study as is required by The University of Glasgow (Code of Good Practice in Research, University of Glasgow, 2016).

### **Who has reviewed the study?**

Scotland A Research Ethics Committee and NHS Highland Research and Development Department have reviewed and provided ethical approval for the study. A member of the course team from the University of Glasgow who is not directly involved in the research has also reviewed the study.

### **If you have any additional questions**

If you have any further questions about the study or would like to discuss it further, please do not hesitate to email me on: [e.boyd.1@research.gla.ac.uk](mailto:e.boyd.1@research.gla.ac.uk) or telephone me on 01463 253697. If you would like to contact someone not directly involved in this study for general advice about taking part in research you can contact Professor Tom McMillan, Research Director, University of Glasgow on 0141 211 3920.

### **What if there is a problem with the study?**

If you are unhappy with the study in any way, first let me know and I will try to resolve any concerns. If you remain unhappy with the response and need to complain formally then please contact NHS Highland feedback team: NHS Highland Feedback Team, PO Box 5713, Inverness, IV1 9AQ, Email: [nhshighland.feedback@nhs.net](mailto:nhshighland.feedback@nhs.net) Phone: **01463 705997**

### **If you feel upset**

**If you feel distressed or upset by any of the information that has been included in this study pack, please do not hesitate to contact me, Emily Boyd, on 01463 253697 or the clinician who gave you this pack so that you can be provided with support.**

### **If you would like to take part**

If you decide that you would like to take part, please contact me to express interest either by email: [e.boyd.1@research.gla.ac.uk](mailto:e.boyd.1@research.gla.ac.uk), by telephone: 01463 253697 or by completing the consent to be contacted sheet (Version 2, 06/03/17) and returning it in the envelope provided. Once I have received this I will contact you to discuss the study further and arrange a suitable time to meet with you. If I have not heard from you within a month of you receiving this information sheet I will assume that you do not wish to take part in the study.

### **If you decide that you do not wish to take part**

You do not have to do anything further.

**I would like to thank you for taking the time to read this information sheet.**

## Appendix 9

### Interview Schedule

This interview schedule was developed by the interviewer and in consultation with my academic supervisor at The University of Glasgow.

Introductions:

- Introduce myself and my role as a researcher/ trainee clinical psychologist
- Thank participant for agreeing to take part in the study
- Remind participant about confidentiality and its limits
- Remind participant they can stop for a break at any point in the interview if they need to do so, and that they can withdraw from participation at any point without providing a reason for doing so. If the participant becomes distressed during the interview they will be asked the question if they wish to proceed with the interview.
- Ask participant if they are okay to begin the interview
- Demographic questions:
  - 1) Age
  - 2) Gender
  - 3) Are you the main carer for your partner?
  - 4) Is there anybody else closely involved in your partner's care?

The questions below will be used to instigate discussion and explore the key areas that are hoped to be covered throughout the interview. It will be emphasised to participants that this is a discussion and there are no right or wrong answers.

#### Gaining a description of partner's dementia

- 1) How long has your husband/wife/partner been living with dementia?
- 2) How has this affected him/her over time?
- 3) What difficulties does he/she have as a result?

#### Exploring the caring role and what it looks like on a daily basis

- 1) Can you describe to me what a typical day of caring for your partner involves?
- 2) Could you tell me about a day that was particularly difficult?
- 3) Could you tell me about a day that you think of as a good day?

Prompts:

- What are the practical implications in terms of daily living e.g. household tasks, financial implications, work and social life?
- What is the emotional impact on you and the person you care for?

### Impact on relationship

6) Has your relationship with your partner changed, if so in what ways?

Prompts:

- Can you tell me about any changes in terms of your one to one relationship with the person you care for?
- Can you tell me about how caring has affected your relationship with friends/family?
- Have any changes occurred in roles (who does what in the home etc)?
- What are the things you cannot do together any longer?
- What do you miss most?
- What do you still do together?
- Are there changes in your relationship that you feel are positive?

### Impact of Rural living on caring role

7) How does living in a rural location impact on your ability to care for your spouse?

Prompts:

- Is there anything about living in a rural location that may make things more difficult for you?
- Are there services that you would like to access but can't due to your location?
- Do you have any difficulties with getting transport to services?
- Do you ever feel isolated?
- What are the positive aspects of living in a rural location?

### Coping with caring

8) How does caring impact on you? What coping strategies do you use?

Prompts:

- How do you cope with stress?
- Are there practical things you do such as talk it through with someone, ask for help? Is this more difficult or easier living in a rural location?
- Can you describe some strategies that you use when things are difficult for you?

### Sources of support

9) What are your main sources of support?

Prompts:

- What supports do you receive from family/ friends/ neighbours?
- What supports have you been offered by services?
- Do you get support from any other sources such as the church or voluntary services?
- What supports are the most helpful?
- What supports are the least useful?
- What enables you to continue to care?
- Do you feel that your sources of support are meeting your needs?

### Final summary question

10) Do you have any suggestions of additional services or sources of support that you feel would assist you as a carer?

\*Provide participant with information resource sheet signposting to services providing additional support.

11) Is there anything else that you would like to tell me that we have not discussed?

**Thank you for your time**

Appendix 10 **DEMENTIA SEVERITY RATING SCALE (DSRS)**

**PARTICIPANT'S NAME:** \_\_\_\_\_ **DATE:** \_\_\_\_\_

**PERSON COMPLETING FORM:** \_\_\_\_\_

Please circle the most appropriate answer.

**Do you live with the participant?** No Yes

**How much contact do you have with the participant?** Less than 1 day per week 1

day/week 2 days/week 3-4 days/week

5 or more days per week

**Relationship to participant**

Self Spouse Sibling Child Other Family Friend Other \_\_\_\_\_

In each section, please circle the number that **most closely applies** to the participant. This is a general form, so no one description may be exactly right -- please circle the answer that seems to apply most of the time.

**Please circle only one number per section, and be sure to answer all questions.**

**MEMORY**

- 0 Normal memory.
- 1 Occasionally forgets things that they were told recently.  
Does not cause many problems.
- 2 Mild consistent forgetfulness. Remembers recent events but often forgets parts.
- 3 Moderate memory loss. Worse for recent events. May not remember something you just told them. Causes problems with everyday activities.
- 4 Substantial memory loss. Quickly forgets recent or newly-learned things. Can only remember things that they have known for a long time.
- 5 Does not remember basic facts like the day of the week, when last meal was eaten or what the next meal will be.
- 6 Does not remember even the most basic things.

**SPEECH AND LANGUAGE**

- 0 Normal ability to talk and to understand others.
- 1 Sometimes cannot find a word, but able to carry on conversations.
- 2 Often forgets words. May use the wrong word in its place. Some trouble expressing thoughts and giving answers.

- 3 Usually answers questions using sentences but rarely starts a conversation.
- 4 Answers questions, but responses are often hard to understand or don't make sense.  
Usually able to follow simple instructions.
- 5 Speech often does not make sense. Can not answer questions or follow instructions.
- 6 Does not respond most of the time.

### **RECOGNITION OF FAMILY MEMBERS**

- 0 Normal - recognizes people and generally knows who they are.
- 1 Usually recognizes grandchildren, cousins or relatives who are **not** seen frequently but may not recall how they are related.
- 2 Usually does not recognize family members who are not seen frequently. Is often confused about how family members such as grandchildren, nieces, or nephews are related to them.
- 3 Sometimes does not recognize close family members or others who they see frequently. May not recognize their children, brothers, or sisters who are not seen on a regular basis.
- 4 Frequently does not recognize spouse or caregiver.
- 5 No recognition or awareness of the presence of others.

### **ORIENTATION TO TIME**

- 0 Normal awareness of time of day and day of week.
- 1 Some confusion about what time it is or what day of the week, but not severe enough to interfere with everyday activities.
- 2 Frequently confused about time of day.
  - 3 Almost always confused about the time of day.
- 4 Seems completely unaware of time.

### **ORIENTATION TO PLACE**

- 0 Normal awareness of where they are even in new places.
- 1 Sometimes disoriented in new places.
- 2 Frequently disoriented in new places.
- 3 Usually disoriented, even in familiar places. May forget that they are already at home.
- 4 Almost always confused about place.

### **ABILITY TO MAKE DECISIONS**

- 0 Normal - as able to make decisions as before.
- 1 Only some difficulty making decisions that arise in day-to-day life.
- 2 Moderate difficulty. Gets confused when things get complicated or plans change.
- 3 Rarely makes any important decisions. Gets confused easily.
- 4 Not able to understand what is happening most of the time.

### **SOCIAL AND COMMUNITY ACTIVITY**

- 0 Normal - acts the same with people as before
- 1 Only mild problems that are not really important, but clearly acts differently from previous years.
- 2 Can still take part in community activities without help. May appear normal to people who don't know them.
- 3 Often has trouble dealing with people outside the home without help from caregiver. Usually can participate in quiet home activities with friends. The problem is clear to anyone who sees them.
- 4 No longer takes part in any real way in activities at home involving other people. Can only deal with the primary caregiver.
- 5 Little or no response even to primary caregiver.

### **HOME ACTIVITIES AND RESPONSIBILITIES**

- 0 Normal. No decline in ability to do things around the house.
- 1 Some problems with home activities. May have more trouble with money management (paying bills) and fixing things. Can still go to a store, cook or clean. Still watches TV or reads a newspaper with interest and understanding.
- 2 Makes mistakes with easy tasks like going to a store, cooking or cleaning. Losing interest in the newspaper, TV or radio. Often can't follow a long conversation on a single topic.
- 3 Not able to shop, cook or clean without a lot of help. Does not understand the newspaper or the TV. Cannot follow a conversation.
- 4 No longer does any home-based activities.

### **PERSONAL CARE - CLEANLINESS**

- 0 Normal. Takes care of self as well as they used to.
- 1 Sometimes forgets to wash, shave, comb hair, or may dress in wrong type of clothes. Not as neat as they used to be.
- 2 Requires help with dressing, washing and personal grooming.
- 3 Totally dependent on help for personal care.

### **EATING**

- 0 Normal, does not need help in eating food that is served to them.
- 1 May need help cutting food or have trouble with some foods, but basically able to eat by themselves.
- 2 Generally able to feed themselves but may require some help. May lose interest during the meal.
- 3 Needs to be fed. May have trouble swallowing.

## **CONTROL OF URINATION AND BOWELS**

- 0 Normal - does not have problems controlling urination or bowels except for physical problems.
- 1 Rarely fails to control urination (generally less than one accident per month).
- 2 Occasional failure to control urination (about once a week or less).
- 3 Frequently fails to control urination (more than once a week).
- 4 Generally fails to control urination and frequently can not control bowels.

## **ABILITY TO GET FROM PLACE TO PLACE**

- 0 Normal, able to get around on their own. (May have physical problems that require a cane or walker).
- 1 Sometimes gets confused when driving or taking public transportation, especially in new places. Able to walk places alone.
- 2 Cannot drive or take public transportation alone, even in familiar places. Can walk alone outside for short distances. Might get lost if walking too far from home.
- 3 Cannot be left outside alone. Can get around the house without getting lost or confused.
- 4 Gets confused and needs help finding their way around the house.
- 5 Almost always in a bed or chair. May be able to walk a few steps with help, but lacks sense of direction.
- 6 Always in bed. Unable to sit or stand.

## **INTERPRETATION**

Add up the points for all sections.

Score

0-18 --- Mild

19-36 -- Moderate

37-54 -- Severe

### **Author:**

Dr. Christopher M Clark, Alzheimer's Disease Core Center  
Department of Neurology, University of Pennsylvania, Philadelphia, Pennsylvania, USA

## Appendix 11

### Consent Form

**Title of study:** A qualitative study on the experiences of providing care at home in rural locations for a partner with dementia

**Name of researcher:** Emily Boyd

**Contact details:**

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IV3 8NP

**Email:** [e.boyd.1@research.gla.ac.uk](mailto:e.boyd.1@research.gla.ac.uk)

**Phone:** 01463 253697

Please write your initial in each box if you agree with the statement:

1. I confirm that I have read and understand the participant information sheet (Version 3, 06/03/17) for the above study

2. I confirm that I have had the chance to consider the participant information and that the researcher has answered any questions to my satisfaction.

3. I understand that my participation is voluntary and that I am free to withdraw from the study at any point without having to give a reason and with no consequences.

4. I understand that I can ask for my data to be withdrawn from the research at any point.

5. I understand that my information will remain held securely and will only be accessible to the research team.

6. I give permission for my interview with the researcher to be digitally recorded.

7. I give permission for anonymised quotations from my interview to be used in reports about the research.

8. I consent to being a participant in this project.

9. I would like to receive a summary of the research once the study has been completed.

\_\_\_\_\_ Signature \_\_\_\_\_ Date

Appendix 12

'Pt4'

Transcript Title: Participant 4

Emergent Themes	Original Transcript (Anonymised post-interview)	Exploratory Comments
<p>PwD concern about money PwD confusion</p> <p>Comparison to caring for a child</p> <p>Change in relationship from wife to carer High level of caring</p> <p>No positive changes in relationship</p> <p>PwD anxiety about leaving house</p> <p>Major impact on carer's life.</p> <p>Local support Local people aware he has dementia</p>	<p>Pt[X]: I says no I'm buying food but pensions go in the joint account and I get, I pay everything out and what's left over will go into one of the ISA's just to get a little bit of interest on it. <u>And he says oh I don't understand that.</u> He's got one statement he got he says why is the top statement, the top figure is higher than the bottom figure and you've got all these payments going in. And I says that's because you've to read it from the bottom. <u>He couldn't get that</u></p> <p>Int: Yeah that's a bit confusing. [coughs]</p> <p>Pt[4]: Look I says at the top this is your total now you know. Why is it? [laughs] <u>it's like having a child sometimes having to explain things to him</u></p> <p>Int: Yeah yeah I think that's what quite a lot of people often say that there are some similarities. Could you maybe talk a bit about your relationship and the transition to becoming a carer? How do you think your relationship has changed, if at all?</p> <p>Pt[4]: [sighs] [pauses] That's a difficult one because <u>it's been so sort of gradual. It's just going from wife to carer it's just I don't know [pause] although lately I suppose I do feel that I'm more like carer than a wife yeah it's just that balance of doing everything else for him. Things that I normally do for him as a wife but it seems to be, going more towards being a carer, it's just, it's not the same at all.</u></p> <p>Int: Yeah and are there any positives things about your relationship emm with the change do you think?</p> <p>Pt[4]: <u>hmm not really I can't think of anything. [pause] because he's relying on me more that's not really a positive thing.</u></p> <p>Int: Are there things that you miss about your relationship?</p> <p>Pt[4]: <u>It's just going out together. Because we used to go, the screen machine comes up I say, lets go and watch a film and before he used to say oh yes it didn't matter what was on we'd go. Now, "no no I don't want to go." "It's too noisy," that's the usual, "it's too noisy, can't leave the dog," same excuses for everything. So</u></p> <p>Int: And how does that then impact on you?</p> <p>Pt[4]: <u>When I can I go on my own but when he's like he was bad the other week and not knowing where I was I just thought I'm was going to go out the next night there was a musical thing on at the hall and I thought, oh I better not leave him. You know I thought because he was moaning about me being out during the day I thought he's not going to be happy about me going out at night. I thought we'll give that a miss. But I do try to get out when I can so</u></p> <p>Int: And has it changed your relationship with your friends and family or people in the village?</p> <p>Pt[4]: <u>hmm no because they are very good in the village because I let them know what's wrong with him so they can understand that and there's one or two that when I have to get out the house I'll go and have a chat with them, let it all out.</u></p> <p>Int: That's really good</p>	<p>PwD trying / wanting to understand money but not able to</p> <p>PwD confusing</p> <p>Comparison to caring for a child</p> <p>Difficult to make a clear distinction?</p> <p>Is this difficult for her to speak about?</p> <p>Change in relationship</p> <p>Description of relationship</p> <p>Level of caring</p> <p>No positive changes in the relationship</p> <p>Increased dependency</p> <p>Change in activities do together as a couple</p> <p>Frustration at this?</p> <p>Carer perceives excuses for not wanting to go</p> <p>Get a sense she is annoyed by this</p> <p>What does she mean by bad? What does this look like?</p> <p>Impacts on carers ability to go out on her own</p> <p>Conflict in the relationship?</p> <p>Local supports. Very supportive</p> <p>Coping strategy; venting to others</p>

## Appendix 13

Abridged table of themes

<b>1) Spousal relationship</b>
<i>Commitment to the relationship</i>
Jessica: "It's gosh it's cemented our relationship you know I love caring for him"
Peter: " I never sort of grudged it, it [caring] was just something I'll do it and that's it"
Sarah: "I've got to do it"
Peggy: "You take your wedding vows, in sickness and in health, so I have to look after him" "I just have to put up with it"
Isobel: "I made a vow when we got married and you know he can't help what's happened"
<i>Change in role</i>
Jessica "We would run things past one another and discuss them and that's hard now not to have that sort of rapport with one another"
Peter: "That's when the caring aspect came home because I thought I done that, I done that, I done that"
Sarah: "It's like having a toddler. Auch its worse you know, this is different"
Peggy: "Lately I do feel that I'm more like carer than wife"
<b>2) Demands of caring</b>
<i>Emotional demands</i>
Jessica: "I was getting more and more het up and crying"
Peter: " Honestly, it gets frustrating"
Sarah: "I cry, I sit and cry I break my heart"
Peggy: "Some days I'm just in tears, you know I go off in tears because I think I can't cope any longer"
Isobel: "I don't often cry but I did on Monday because I was so frustrated"
<i>Magnitude of caring</i>
Jessica: "It's a big learning curve"

Peter: "It's 24/7 day after day" "It's not just a simple thing that they forget things its all the other things that come along with it. The mood swings, the incontinence, everything you know, their health. It affects the whole being doesn't it?"

Sarah: "I'm hardly getting anytime at all to myself at night"

Peggy: "It's hard work for me too"

Isobel: "Hellish. Is roughly how I would put it... it's hard work and it's 24/7"

### 3) Managing the demands

#### *Satisfaction with Formal sources of support*

Jessica: "She [CPN] always emailed back straight away so I knew the support was there"

Peter: "You can't fault the support and help and advice and information you know"

Sarah: " [The CPN] comes once a month, you couldn't get any nicer, she's lovely she really is"

Peggy: " It think it's quite good for a rural area, it's quite good really."

Isobel: "I think the services are good... it's knowing where to access them"

#### *Local support/ community*

Jessica: "Everyone knows us ... I know they would drop whatever they were doing and help us."

Peter: "Staying in that sort of community is great because you know there is always somebody you can phone."

Sarah: "Luckily everybody in the village... they know he's got dementia."

Peggy: "They are very good in the village because I let them know what's wrong with him, so they can understand that."

Isobel: "Especially in [the village] if there was a problem, somebody would come in and get me [because they know the couple]."

#### *Coping strategies*

Jessica: "I do still have some 'me' time" "You've got to make time to do things"

Peter: "I've had quite a good placid nature and attitude all my life you know to sort of deal with things"

Sarah: "I blow my top and that's it"

Peggy: "I just let off steam or if not I go off in the car, I drive somewhere, have a rant and when I've calmed down I'll go back"

Isobel: "I'm either in the greenhouse or trying to finish that wee project out there just something you know just something different to stop you thinking about what is going on"

#### 4) Unmet needs

##### *Resources for person with dementia*

Jessica: "The G.P. couldn't find a psychiatric bed anywhere in Scotland so he went to the general hospital for 6 nights"

Peter: "You can do the services through the NHS but they are so short staffed... you could wait for months"

Sarah: "He [NHS care worker] used to come one day a week but he's changed it to, I think he's got so much on his plate, and he comes once every 2 weeks"

Peggy: "A day centre for [my husband] would be good"

Isobel: "Whether it is OT or physio or nurses they don't seem to...phone you up and just check that you're surviving"

##### *Resources for carers*

Jessica: "If I lived in [the town] then yes I could go [to the carers group]"

Sarah: Interviewer: "What sources of support do you have for yourself as a carer? I don't have anything"

Peggy: "They said we'll get someone to ring you but they never got back to me"

Isobel: "Nobody turned round and said how are you?"

##### *Rurality*

Jessica: "The big one is no mobile reception. Because we have no mobile reception we can't use the GPS tracker."

Sarah: "I'm definitely isolated" "The bus service is garbage"

Isobel: "It's very isolating" "We had to get the emergency ambulance which took forever as it was stationed at [remote village]"

## Appendix 14

### Proposal

**Title of Project: A qualitative study on the experiences of providing care at home in rural locations for a partner with dementia**

### Abstract

#### *Background*

It is estimated that there are around 850,000 people in the United Kingdom living with dementia (Prince et al., 2014). Many individuals are cared for in residential settings, particularly in the later stages of the condition. However, two thirds of people with dementia remain cared for in their own home (O'Shaughnessy, Lee & Lintern, 2010). There are a shortage of studies which have looked at the experiences of relatives caring for a partner in the later stages of dementia and a lack of research focusing on the impact of rurality on care giving.

#### *Aims*

This study aims to determine the lived experiences of caring at home for a partner with the later stages of dementia in rural populations. It will focus on determining their experiences of coping, their needs and any other issues they encounter.

#### *Method*

Participants will be individuals who are caring at home for a partner in the later stages of dementia. They will be recruited from rural populations across NHS Highland. Data

will be gathered through the use of semi-structured interviews. Interpretative phenomenological analysis (IPA) will be used to analyse the interviews.

### *Application*

The results of the study will give insight into the experiences of caring for a partner with dementia in rural locations. It is hoped that this will provide information that will assist the development of future services and identify unmet needs of this specific population.

## **Introduction**

As life expectancy increases and mortality rates decrease, dementia is increasingly becoming a leading cause of death (Hennings, Froggatt & Keady, 2010). Many people with dementia are cared for in residential settings, particularly in the later stages of the condition. However, two thirds of people with dementia remain cared for in their own home (O'Shaughnessy et al., 2010). The burden of care giving usually falls to family members who may end up caring for an individual with dementia at home for many years. Family carers of people with dementia save the United Kingdom £11 billion a year (Prince et al., 2014)

The specific nature of dementia and its trajectory makes the context of care giving unique. People with dementia experience progressive physical and cognitive losses, which result in the person requiring increasing assistance from caregivers (Quinn, Clare, Pearce & Van Dijkhuizen, 2008). This can put growing stress, strain and

burden on family carers (Etters, Goodall & Harrison, 2007). Caregiver burden is defined as a “multi-dimensional response to the negative appraisal and perceived stress resulting from taking care of an ill individual” (P.846 Kim, Change, Rose & Kim, 2011). The burden of caregiving is associated with reduced outcomes for caregivers such as illness, a reduction in their quality of life and depression (Schulz, Boerner, Shear, Zhang & Gitlin, 2006). This can have a negative impact on the care that they are able to provide and can also lead to poorer outcomes for recipients of care such as a poorer quality of life and early residential care placement (Gaugler, Kane, Kane & Newcomer, 2005).

Spouses face changes in their relationship when they care for a partner with dementia (O’Shaughnessy, et al., 2010). Roles within the relationship may change, for example a spouse will often become the main decision maker in the person with dementia’s life. As the person’s dementia continues into the later stages of the condition the caregiver may experience a series of losses which have been described as pre-death grief (Muders, Zahrt-Omar, Bussman, Haberstroh & Weber, 2015).

Aspects of rural living such as limited transportation and reduced access to health professionals and certain community-based programs may all impact on care giving. In comparison to the wider literature on experiences of caregiving, there is a relative lack of research of caregivers in remote and rural settings (Sun, Kosberg, Kaufman & Leeper, 2010). A systematic review (Innes, Morgan & Kostineuk, 2011) concluded that to date, research on family dementia care giving has focused on the barriers and experiences of accessing formal service provisions. They expressed a need for more research on the impact of rurality on care giving and the support needs of rural care givers.

In recent years there have been an increasing number of studies researching dementia with an emphasis on the earlier stages of the disorder, specifically on receiving a diagnosis (Pratt & Wilkinson, 2003). Carers report that their experiences of caring for a partner with the early stages of dementia include struggling to make sense of dementia and its impact on their relationship with the care recipient, stress related to adjusting to these changes and a need to focus on coping day to day (Quinn, Clare, Pearce & Van Dijkhuizen, 2008). There is a relative lack of studies which have focused on the carers experiences of caring for a relative in the later stages of dementia (Meuser & Marwitt, 2001).

Although there has been more recognition in the literature of the needs of carers, these studies have tended to focus on factors that influence outcomes for caregivers and have used surveys and structured interviews with predetermined categories to obtain this information (Shanley, Russell, Middleton & Simpson-Young, 2011). Studies which have used these methodologies identified that carers seek effective communication and guidance from professionals (Hennings et al., 2010) and have a desire to receive more practical and psychological support (Muders, et al., 2015). They identified that carers and families would like their own needs considered and cared for and struggled to cope with the simultaneous personal needs of care-giving and grieving (Hennings et al., 2010). A systematic review (Stolz, Uden & Willman 2004) concluded those who care for an older family member at home fear social isolation and have a desire to have increased contact with peers. They also identified family carers desire respite care for their relative and experience burden, stress and worry when providing care.

These studies provide useful insights into care givers experiences of caring for a relative at home. However, there is a relative lack of studies which have been conducted in ways that are flexible enough to take into account carers' own views and gain a sense of their lived experiences. Qualitative methodology would address some of these concerns.

The present study will investigate the experiences of caring at home for a partner with dementia. Specifically, participants will be recruited who are caring for a partner with late stage dementia and those who are living in rural populations across NHS Highland.

### **Aims**

This study aims to determine the lived experiences of caring at home for a partner with late stage dementia in rural areas.

Objective: Semi-structured interviews will be used to determine participants' experiences of coping, their needs and any other issues they encounter.

## Plan of investigation

### Participants

Participants will be people who are caring at home for a partner in the later stages of dementia. They will be living in rural settlements in NHS Highland.

### Inclusion and Exclusion Criteria

Inclusion criteria will be individuals who have had the experience of caring for their partner who is in the later stages of dementia who is being cared for at home. The later stages of dementia, defined as moderately severe cognitive decline, will be measured by The Dementia Severity Rating Scale (DSRS) (Clark & Ewbank, 1996). A further inclusion criterion is that participants will live in rural areas of NHS Highland. Rurality will be determined by those living in populations of less than 3000 people (The Scottish Government, 2012).

Exclusion criteria will include:

- Carers whose partner is in the early stages of dementia – defined as scoring less than 18 on the DSRS (Clark & Ewbank, 1996).
- Carers who have dementia themselves
- Carers who live in urban areas
- Carers whose English is not fluent
- Carers who are caring for a partner with young onset dementia

## Recruitment

Participants will be recruited through the older adult community mental health teams (CMHT's) in NHS Highland. Members of the team will screen potential participants for rurality by postcode, and provide potentially suitable participants with a study pack containing a covering letter, a participant information sheet, a copy of the consent form, a consent to being contacted form and a copy of the DSRS (Clark & Ewbank, 1996). Interested participants will be asked to contact the researcher to express interest in the study either by email, by telephone or by completing the consent to being contacted form and posting it back to the researcher. The researcher will then contact interested participants by telephone, answer any questions about the study and ensure eligibility. The DSRS (Clark & Ewbank, 1996) will be administered by telephone. Participants will also have a paper copy to refer to from the study pack. The researcher will review the information provided and if all inclusion criteria of the study are met, a suitable time will be arranged to conduct the interview.

## Procedures

Interviews will either take place at local NHS premises (either G.P. surgeries local to participants or a local community hospital) or at the participant's home if all of the criteria for home visits are met (as outlined in Appendix 2). Telephone interviews will also be offered to participants. All participants will have received written information about the study in advance. At the time of meeting to conduct the interview, the information they were provided with will be reviewed and participants will be asked if they have any further questions regarding the study. If participants are happy to proceed with the interview, informed written consent will be taken by the researcher.

Participants will be interviewed on a one to one basis about their experiences of providing care at home to their partner. Interviews will last approximately one hour. The interview schedule will be semi-structured. Interviews will be recorded on a digital voice recorder and transcribed verbatim. Interview transcripts will be anonymised for references to person or place. Transcripts of the interviews will be stored on a University of Glasgow laptop with full disc encryption. Any information in paper form related to the study, for example consent forms, will be stored in a locked filing cabinet in NHS Highland premises. Interpretative phenomenological analysis (IPA) will then be used to interpret the data.

## Measures

The DSRS (Clark & Ewbank, 1996) will be completed with the carer of the person with dementia to determine what stage of dementia the person is currently at. The DSRS has high test-retest reliability; the reliability co-efficient on a sample of 19 patients scores at two time points was calculated to be 0.90 (Clark & Ewbank, 1996). With regards to interrater reliability, a sample of 15 patients were rated by a physician, a care giver and a research associate. The correlations between all pairs of score were calculated to be higher than 0.87 (Clark & Ewbank, 1996), outlining that the DSRS (Clark & Ewbank has high inter-rater reliability. The focus of this study is on the experiences of caring for those with moderate to severe cognitive decline. Clark & Ewbank (1996) outline the following cut off scores on the DSRS to determine dementia severity: scores of 0-18 are described as the person experiencing mild symptoms of dementia, scores of 19-36 are described as moderate symptoms and finally scores of 37-54 are described as severe. Participants scoring 19 or above on the scale will be invited to take part in this study.

Semi- structured interviews will be the predominant method of data capture. The interview schedule was developed by the researcher and in consultation with the researcher's academic supervisor at The University of Glasgow.

## **Design**

The design of the study is qualitative using semi-structured interviews. Interpretative phenomenological analysis (IPA) will be used to analyse the interviews. This methodology aims to give insight into how a person makes sense of a particular phenomenon. It is concerned with the meanings which those experiences hold for individuals. The researcher's own interpretations of the individual's experience are also taken into account using IPA.

## Data Analysis

Transcription and analysis of interviews will begin after the first interview has been completed in order to inform and make any necessary amendments to the interview schedule. After the interviews have been transcribed, the original transcripts will be read and re-read in order to become familiar with the data. Anything of interest at this point will be noted before the emergent themes are developed across the transcript. After this part of the analysis has been completed, connections across cases will be made, looking for patterns of emergent themes. A key aspect of IPA is awareness of the researcher's own interests and preconceptions which they bring to the interpretation of another individual's experiences. Preconceptions may be identified in advance of the interviews but they may also emerge during the process of the

research. Therefore, the researcher will keep a reflective diary of observations and interpretations throughout the research process in order to become more aware of these issues. The project supervisors will take a small sample of transcripts annotated with categories or themes and check annotations have validity in relation to the text being examined (Smith, Flowers & Larkin, 2009).

#### Justification of sample size

The study will explore experiences of caring within a homogeneous sample (the later stages of dementia and living in a rural population). Smith et al. (2009) recommend a sample size of between four and ten interviews for doctoral level IPA research. The focus in IPA research is on gaining detailed information on participants' experiences as opposed to a focus on the generalizability of data. Therefore this number of participants is anticipated to be able to generate sufficient insights to usefully explore the experiences of these carers.

### **Health and safety issues**

#### Participant Safety Issues

There may be some distress associated with taking part in the study. It is potentially a particularly emotive subject for the partner discussing difficult issues related to caring at home for their partner. At the end of the interview, all participants will be provided with information that signposts them to further sources of help and local carer services. If a participant becomes distressed during the interview, they will be offered a break and the option to stop the interview. It will be emphasized to participants at the beginning of the interview that they can stop the interview at any point in the

process without providing a reason for this. It will be stressed that this will have no impact on the care that they receive or any services that they access currently or in the future.

### Researcher Safety Issues

Interviews will take place at local NHS premises (either G.P. surgeries or a community hospital). If the carer cannot attend then there is a possibility that the interview could be conducted at the carer's house. This will only occur if a full risk assessment has been carried out by another health professional who is currently involved with the family and has had recent contact.

### **Ethical issues**

Ethical approval for the project will be sought from NHS research ethics committee.

Participants will be provided with written information about the study and a copy of the consent form to review in advance of meeting for the interview. Participants will be given the opportunity to ask questions about the study prior to completing the consent form.

It will be emphasized to participants that they can withdraw from the study at any point in the research process without providing a reason for doing so. It will be made clear that this will have no impact on any services that participants currently receive, or will receive in the future.

In order to maintain confidentiality, participants' details will be anonymised. Transcripts of the interviews conducted will be given pseudo names so that the interview scripts can only be identified by the researcher. Interview transcripts will be

stored on an encrypted laptop and any paper information will be held in a locked cabinet. Data will be held securely for a period of ten years after the completion of the study as is required by The University of Glasgow (Code of Good Practice in Research, University of Glasgow, 2016)).

### **Financial issues**

The costs for this study will include stationary for recruitment packs containing initial information sheets and consent forms. Recording and transcription kits will be borrowed from the University of Glasgow. An encrypted laptop, borrowed from the University of Glasgow, will be used to store interview recordings and transcripts.

### **Timetable**

Ethics submitted: October 2016

Recruitment: October 2016 – February 2017

Interviews conducted & analysis: October - February 2017

Write up: March-May 2017

Submission: July 2017

### **Practical Applications**

The results of the study will give insight into the experiences of caring for a partner with dementia. It is hoped that this will provide information that will assist the development of future services and identify unmet needs of this specific population.

The results may also provide suggestions for further research.

## References

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